The development of an instrument to measure adolescent HIV self-management in the context of the Western Cape, South Africa

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DECLARATION

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third-party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Introduction and rationale: South Africa is home to 20% of the global human immunodeficiency virus (HIV)-infected adolescent population of 1.8 million. The clinical HIV management of adolescents may be challenging and are compounded by the physical and psychological changes that occur during adolescence. With the advent of antiretroviral treatment access, HIV is managed as a chronic disease and elements such as self-management become an important component of care. Research to date has not focused on adolescent HIV self-management or the measurement thereof.

Aim: To develop an instrument to measure adolescent HIV self-management in the context of the Western Cape, South Africa.

Methods: A mixed-method explorative sequential design was used. The study setting included selected healthcare facilities in the Cape Metropole of the Western Cape. Adolescents aged 13 to 18 who attended HIV services, their caregivers and healthcare workers/academics experienced in adolescent HIV care and research, were the target population groups.

Individual interviews were conducted with six adolescents, six caregivers and six healthcare workers, followed by five focus groups with adolescents. Interpretive phenomenology was used to situate the experiences of participants in their social and cultural context. In the second study phase, items were inductively developed based on the participants' experiences, the theoretical framework for the study and literature. Thirdly, adolescents and caregivers in focus groups had an opportunity to evaluate whether the developed items resonated with their experiences using cognitive questioning. Following this, a group of experts evaluated the content validity and clarity of each item thereby reducing the initial 65 items to 44 highly relevant items. Participants were purposefully selected for the more qualitative components. Finally, in the fourth phase of the study, in order to establish validity and reliability, a cross-sectional design was used and the self-administered questionnaire was completed by 385 adolescents who were sampled serially from 11 healthcare facilities in the Cape Metropole.

Findings: Five components of adolescent HIV self-management were identified though exploratory factor analysis: *Believing and knowing*; *Goals and facilitation*; *Participation*; *HIV biomedical management*; and *Coping and self-regulation*. These components were meaningful and could be related to the theoretical framework for the study and the qualitative data. The final Adolescent HIV Self-Management (AdHIVSM) measure consisted of 35 items. The developed AdHIVSM-35 had acceptable reliability and stability. The sub-scales had

acceptable reliability, but some of the sub-scales had undesirable stability and questionable convergent validity. Confirmatory factor analysis on the structure developed through exploratory factor analysis indicated a good model-fit that supported its structural validity.

The study provides evidence that participants who have higher self-management had better HIV-related and general health outcomes, which supports the criterion- and convergent validity of the identified components.

Conclusion: Targeting adolescent HIV self-management in the clinical HIV management setting has the potential to improve adolescents' adherence to treatment, viral suppression rates and their health-related quality of life.

Key words: HIV, adolescents, self-management, instrument development

OPSOMMING

Agtergrond en rasionaal: Suid Afrika huisves 20% van die wêreldwye menslike immunogebreksvirus (MIV)-geïnfekteerde adolessente populasie van 1.8 miljoen. Die kliniese MIV bestuur van adolessente mag uitdagend wees en word vererger deur die fisieke en psigologiese veranderinge wat gedurende adolessensie plaasvind. Met die koms van en toegang tot antiretrovirale terapie, word MIV soos 'n kroniese siekte behandel en het aspekte soos self-bestuur 'n belangrike komponent van sorg geword. Navorsing het tot op hede nie op adolessente MIV self-bestuur en die meet daarvan gefokus nie.

Doel: Om 'n instrument wat adolessente MIV self bestuur in die konteks van die Wes Kaap, Suid Afrika meet, te ontwikkel.

Metodes: 'n Gemengde-metode verkennende sekwensiële ontwerp was gebruik. Die studie omgewing het geselekteerde gesondheidsorgfasiliteite in die Kaapse Metropool van die Weskaap ingesluit. Adolessente tussen die ouderdom van 13 en 18 wat MIV dienste gebruik, hulle versorgers, gesondheidsorgwerkers/akademici met ondervinding in adolessente MIV sorg en navorsing, was die teiken populasie groepe.

Eerstens was individuele onderhoude met ses adolessente, ses versorgers en ses gesondheidsorgwerkers gevoer en daarna is vyf fokusgroepe met adolessente gehou. Interpretatiewe fenomenologie was gebruik om die ervaringe van die deelnemers binne hulle sosiale en kulturele konteks te plaas. In die tweede fase van die studie is items, gebaseer op die deelnemers se ervaringe, die teoretiese raamwerk van die studie en die literatuur induktief ontwikkel. Derdens het adolessente en versorgers die ontwikkelde items se resonansie met hulle ervaringe geëvalueer in fokusgroepe waar kognitiewe onderhoudsvoering gebruik is. Hierna is 'n groep kenners gevra om die inhoudgeldigheid en duidelikheid van elke item te evalueer en die inisiële lys van 65 items is na 44 hoogs relevante items verminder. Deelnemers was doelgerig geselekteer vir hierdie kwalitatiewe komponente. Laastens, in die vierde fase van die studie, om geldigheid en betroubaarheid te bepaal, is 'n deursnit ontwerp gebruik en is die self-toegediende vraelys deur 385 adolessente voltooi wat van 11 gesondheidsorgfasiliteite in volgorde geselekteer was.

Bevindinge: Vyf komponente van adolessente MIV self-bestuur is deur verkennende faktor analise geïdentifiseer: *Glo en weet*; *Doelwitte en fasilitering*; *Deelname*; *MIV biomediese bestuur*; en *Hantering en selfregulering*. Hierdie komponente het betekenisvol met die teoretiese raamwerk en kwalitatiewe data ooreengestem. Die finale Adolessente MIV

Selfbestuur (AdMIVSB) meetinstrument het uit 35 items bestaan. Die AdMIVSB-35 se betroubaarheid en stabiliteit was aanvaarbaar. Die sub-skale het aanvaarbare betroubaarheid gehad, maar sekere sub-skale se stabiliteit en konvergente geldigheid was ontoereikend. Bevestigende faktor analise wat toegepas was op die instrumentstruktuur wat deur verkennende faktor analise ontwikkel is, het 'n goeie modelpassing aangedui, wat die geldigheid van die struktuur bevestig het.

Die studie verskaf bewyse dat deelnemers met hoër self-bestuur beter MIV-verwante en algemene gesondheid resultate gehad het, wat die maatstaf- en konvergente geldigheid van die geïdentifiseerde komponente bevestig.

Slotsom: 'n Fokus op adolessente MIV self-bestuur in die kliniese MIV bestuur van adolessente het die potensiaal het om adolessente se getrouheid tot hulle behandelingsplan, virus onderdrukkingsvlakke en gesondheidsverwante kwaliteit van lewe te verbeter.

Sleutelwoorde: MIV, adolessente, self-bestuur, instrumentontwikkeling

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"*Carry one another's burdens and in this way you will fulfil the requirements of the law of love.*" (Galatians 6:2)

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral treatment
HIV	Human Immunodeficiency Virus
SM	Self-management
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

CHAPTER 1
FOUNDATION OF THE STUDY

1.1 INTRODUCTION

Approximately 1.8 million adolescents between the ages of 10 and 19 were living with the Human Immunodeficiency Virus (HIV) in 2015 worldwide, with more than 80% (1.4 million) living in sub-Saharan Africa (United Nations Children's Fund (UNICEF), 2016:32). Adolescents represent a growing proportion of people living with HIV globally and in 2015, 250 000 adolescents between the ages of 15 and 19 were newly infected with HIV (UNICEF, 2016:32). The distribution of HIV among adolescents in sub-Saharan is uneven with one in three newly infected young people coming from either Nigeria or South-Africa (Adejumo, Malee, Ryscavage, Hunter & Taiw, 2015:2). South Africa is home to 20% of the global adolescent HIV-infected population (UNICEF, 2016:32).

The World Health Organisation (WHO) defines adolescence as the age group from 10 to 19 years and distinguish between early (10-14) and late (15-19) adolescence (WHO, 2014:2). 'Youth' generally refers to individuals in the 15 to 24 year age group and 'young people' is a combined concept for adolescence and youth (WHO, 2010:14).

Due to effective antiretroviral treatment (ART) available to infants and children, a generation of perinatally-infected children has entered adolescence (Gray, 2009:1; Sohn & Hazra, 2013:185). Some of these children may have been lost to follow-up. A number suffer from impaired neurocognitive development, delayed sexual maturation, emotional and behavioural problems and long-term ART adverse effects (Adejumo et al., 2015:4). In addition to the population of perinatally-infected adolescents, hundreds of thousands of adolescents may become newly infected with HIV in the coming years and require lifelong ART if current trends continue (UNICEF, 2016:32).

Globally care for HIV infected adolescents is lacking effectiveness, as indicated by the increase in Acquired Immune Deficiency Syndrome (AIDS) related deaths amongst adolescents in the period 2000 to 2015. More than 100 adolescents died of AIDS every day in 2015 and AIDS is now the leading cause of death amongst adolescents aged 10 to 19 globally, especially in sub-Saharan Africa (UNICEF, 2016:2; 34). South Africa has also made insufficient progress to reduce HIV/AIDS mortality among the youth (De Wet, Oluwaseyi & Odimegwu, 2014:13).

Adolescents who know their status and who are able to access ART may encounter challenges such as stigma, discrimination and a lack of support for taking treatment, leading

to poor treatment outcomes (Adejumo et al., 2015:1; UNICEF, 2016:34). A study conducted in urban Gauteng, South Africa found that HIV infected adolescents and young adults between 15 and 24 years of age have worse ART outcomes compared to adults receiving ART (Evans, Menezes, Mahomed, Macdonald, Untiedt, et al., 2013:892). Turning the tide against HIV will therefore require interventions focused on adolescents.

The 'All In to End Adolescent AIDS' agenda was launched in 2015 to better position the global AIDS response to end the AIDS epidemic among adolescents by 2030. One of the aims is to reduce AIDS related deaths amongst adolescents by 65% by 2020 (UNICEF, 2016:32). This will require innovative strategies to identify and support adolescents who are taking ART to remain in care and to adhere to treatment. In addition, there is a renewed focus on assisting adolescents to optimally live with HIV and support them in their pursuit for social and economic participation (Mofenson & Cotton, 2013:186). This requires a patient-centred approach to treatment and care.

With the advent of ART, HIV is managed as a chronic condition and self-management is an important component of care (Sawin, Bellin, Roux, Buran & Brei, 2009:26; Modi, Pai, Hommel, Hood, Cortina, Hilliard, et al., 2012:473). Self-management is a patient-centred approach to care and there is empirical support that the health outcomes of individuals and families who engage in self-management improve (Ryan & Sawin, 2009:217).

When considering the global rise in chronic diseases such as HIV, the WHO definition of health as the complete physical, mental and social well-being of a person, may not be realistic and fit for purpose anymore (Huber, Knottnerus, Green, van der Horst, Jadad, Kromhout, et al., 2011: 343). The present healthcare system is neither effective nor efficient due to the dichotomy of acute versus chronic disease management approaches (Holman & Lorig, 2004:239). Huber et al. (2011:343) suggests re-defining health as "the ability to adapt and self-manage in the face of social, physical, and emotional challenges". This means that the patient should be an active partner in the care process (Holman & Lorig, 2004:240) and that healthcare providers should provide support for the physical, emotional and social challenges these patients may face.

Van Staa (2012:18) states that chronic disease often adversely affects social participation and health-related quality of life of adolescents, but studies exploring how growing up with a chronic disease affects the lives of adolescents are still scarce. Since HIV has only recently been considered a chronic disease, even fewer studies have looked at how being diagnosed with HIV at a young age influences individual well-being, optimal development, activities and social participation of young people. The WHO International Classification of Functioning (ICF) defines an activity as "the execution of a task by an individual" such as learning and

applying knowledge, general tasks, communication, mobility and self-care; and participation as "the involvement in a life situation" for example, domestic life, interpersonal life/relationships, major life activities and community life (WHO, 2002:10,16). Living with HIV may have many consequences for adolescents that can affect their ability to perform certain activities and participate socially, ultimately influencing their quality of life.

Managing adolescents living with HIV poses several challenges such as motivating adherence to lifelong treatment and managing complications from HIV (Mofenson & Cotton, 2013:186; Nachega, Hislop, Nguyen, Dowdy, Chaisson, et al., 2009:65). Adolescents, especially those infected perinatally, need to transition from being completely dependent on adults for their care, to becoming more self-reliant in adult or mixed care settings since there is no clinical context that is specialised in their care (Sohn & Hazra, 2013:185). This transition combines with their own developmental pursuit for identity formation and independence. Van Staa (2012:23) states that this transition process involves a large amount of daily work by adolescents and families to cope with stressors and adaptive tasks imposed by the chronic condition. We know little about how adolescents living with HIV and their families are managing their disease and how they perceive its impact on their lives.

1.2 BACKGROUND AND RATIONALE

Prior to the countrywide implementation of the prevention of mother-to-child transmission (PMTCT) of HIV programme in 2004, many children in South Africa acquired HIV perinatally (Simelela & Venter, 2014:249). Even with an effective PMTCT programme in place, some children may still acquire HIV perinatally. The current mother-to-child transmission rate in South Africa is 2.6% compared to a 20%-30% transmission rate prior to PMTCT (Goga, Jackson, Singh & Lombard, 2015:i). Previous South African guidelines recommended the initiation of combination ART for all children who test positive for HIV under the age of five years. The South African government extended this and current guidelines prescribe ART for all patients living with HIV irrespective of age or health status (Department of Health, 2016:1).

As children and adolescents who live with HIV grow older, they face various challenges with regard to the effects of HIV on their physical, psychological and social development. In addition, they have to adhere to lifelong ART. Challenges include physical and emotional developmental delays, the transition from paediatric to adult care, adhering to medication, treatment fatigue, access to services, initiation of sexuality, adopting safe sexual practices, reduction of risk behaviours, acquiring a quality education and taking responsibility for their own health (Mofenson & Cotton, 2013:186). There is, therefore, a unique opportunity to assist adolescents, whether they are long-term survivors of perinatally transmitted HIV or were behaviourally infected, as they approach adulthood (UNICEF, 2010:15).

Adolescents in low-resource countries tend to start ART much later and therefore may have more severe morbidity (Agwu & Fairlie, 2013:185). HIV infection acquired when the immune system is still immature may result in clinical complications such as chronic lung, cardiac, skin, renal and bone diseases as well as growth failure and neurocognitive disorders (Lowenthal, Bakeera-Kitaka, Tafirey, Chapman, Goldrath & Ferrand, 2014:2). Further, socioeconomic dilemmas such as poverty, low levels of education, being an orphan, community and family violence, child abuse, and alcohol or drug use are rife in low-resource countries, especially South Africa (UNICEF, 2013b:5). Over and above, HIV-infected adolescents face stigma and discrimination, the fear of being different and an uncertain future. The cumulative psychological stressors places HIV-infected adolescents at risk for poor mental health, including behavioural problems and psychiatric disorders such as post-traumatic stress disorder, depression and severe anxiety (Lowenthal et al., 2014:8, 9).

In Africa, adolescent tailored health services are scarce and healthcare workers lack experience in adolescent counselling and support (Agwu & Fairlie, 2013:185; Lowenthal et al., 2014:12). Consequently, adolescent care in low resource settings is fraught with problems, which may negatively affect the clinical outcomes of adolescents. The abovementioned therefore necessitates an investigation into how to improve care for adolescents living with HIV in low resource settings.

One possible intervention to improve the clinical outcomes of adolescents is self-management support. Modi et al. (2012:475) broadly defines paediatric self-management (SM) as "the interaction of health behaviours and related processes that patients and families engage in to care for a chronic condition". It can also be defined as the daily tasks (e.g. managing symptoms, treatment, physical and psychosocial consequences and lifestyle changes) a person living with a chronic disease needs to integrate into their daily life in order to manage their illness and promote health (Webel, Asher, Cuca, Okonsky, Kaihura, et al., 2012:74). These daily tasks require skills such as problem solving, decision making, resource utilisation, forming partnerships with healthcare providers and taking action (Lorig & Holman, 2003:1).

The term self-management (SM) can refer to a process, a programme or an outcome (Ryan & Sawin, 2009:219). The process of self-management may refer to the use of self-regulation skills and activities such as goal-setting, self-monitoring and management of physical, emotional and cognitive responses associated with health behaviour change. SM processes are a dynamic interaction among the following: a) condition-specific knowledge and beliefs, b) acquisition and use of self-regulation skills and abilities and c) social facilitation and negotiation (Ryan & Sawin, 2009:220). SM programmes help persons with chronic diseases self-manage their illness. SM outcomes (also referred to as SM behaviours) are the result of persons engaging in self-management processes for example, good adherence to treatment

(Ryan & Sawin, 2009:219). In this study, the term SM refers to the processes and behaviours of self-management.

Self-management is different from self-care. Although the terms are related, self-care refers to the performance of activities of daily living, whereas, SM focuses on managing all the components of living with a chronic illness and partaking in healthy behaviours (Ryan & Sawin, 2009:219).

Self-management is also not synonymous with treatment adherence, since concepts such as adherence and compliance are contrary to the notion that the individual and family are the primary role players in chronic care management (Ryan & Sawin, 2009:225). However, SM is very likely to influence treatment adherence in a clinically relevant way (Modi et al., 2012:480) as well as the quality of life of adolescents (Schilling, Dixon, Knafl, Lynn, Murphy, et al., 2009:228). Knowledge of adolescent HIV SM may therefore give valuable insights into which interventions are necessary to improve clinical outcomes such as treatment adherence and the quality of life of adolescents.

The keystones for transfer readiness (transfer to adult care) are adolescents' attitude to transition and the level of their self-efficacy in managing self-care. A biomedical model focused on clinical outcomes may therefore not sufficiently prepare adolescents with chronic conditions for adult care (Van Staa, 2012:283). In order to optimise healthcare for HIV-positive adolescents, HIV-specific transitional services that are integrated and evidence-based, needs to be implemented (Lee & Hazra, 2015:1).

Few instruments measure aspects of health such as SM, adaptation and physiological resilience (Huber et al., 2011:343). In order to assess the components of adolescent HIV self-management, we need a good quality measure. Instruments to assess SM have been developed for the use in adults living with HIV (Wallston, Osborn, Wagner & Hilker, 2010:109; Webel et al., 2012:72) and for adolescents with chronic diseases such as diabetes (Schilling et al., 2009:228) and spina bifida (Sawin et al., 2009:37). There is however no instrument to assess adolescent HIV SM and its components, especially in low resource settings within a socio-cultural complex environment such as South Africa. Until now there has been no inductively designed and psychometrically-tested instrument to measure HIV self-management in adolescents.

The availability of a valid and reliable instrument to assess adolescent HIV SM has the potential to be a valuable clinical management tool to identify adolescents' SM needs, and measure the effectiveness of adolescent SM support interventions in high HIV prevalence settings.

The science of SM is still in a developmental stage. Nursing research focused on exploring SM in different population groups will further build the science base for SM and future research (Schiffman, 2016).

1.3 RESEARCH PROBLEM

There is limited evidence regarding SM in adolescents with HIV, especially in the African and sub-Saharan African context. A study done in Zambia by Denison, Banda, Dennis, Packer, Nyambe, et al. (2015:1) reported that adolescents living with HIV had few SM skills to help them take ART regularly. Adolescents in low resource settings may experience contextual, developmental and cultural specific challenges related to SM that may influence how they relate to healthcare treatment plans.

Currently, in Africa and South Africa, the majority of adolescents living with HIV receive care in health facilities that may or may not have separate HIV and/or adolescent services (Lowenthal et al., 2014:12). Very few healthcare providers have training or an interest to work with adolescents. Healthcare providers further consider adolescents as a complex group to manage due to various behaviour problems that result in non-adherence to treatment and ultimately treatment failure. Most countries are unable to track the adolescent HIV epidemic and/or adolescent HIV-related outcomes effectively (UNICEF, 2016:37).

Although South-Africa has a large HIV-positive adolescent population and many adolescents are on ART, there are no national level estimates of retention in care and it remains unclear which adolescents are most likely to drop out of care in South Africa (Maskew, Fox, Evans, Govindasamy, Jamieson, et al., 2016:2). Knowledge of SM skills and behaviours in adolescents with HIV may help healthcare providers to tailor interventions focused on the needs of adolescents that may improve their health outcomes.

Access to ART made HIV a chronic disease and elements of chronic disease management such as SM have become an important component of care. Research to date has not focused on adolescent HIV SM. Although there are some existing biomedical outcome measures such as viral load monitoring and retention in care, there is no known instrument to measure adolescent HIV SM in a South African context. A comprehensive measure of SM is necessary in order to identify with which aspects of SM adolescents living with HIV need help, to decrease morbidity and mortality. HIV clinicians and counsellors may identify adolescents at risk for non-adherence using the SM measure. Without a valid and reliable measure, we cannot assess the effect of new SM interventions accurately. Further, the importance of the cross-cultural validation of instruments are often underplayed. This may be due to the rigorous and time-consuming methodological process required to obtain an instrument that is valid and reliable to measure the construct in the target population (Sousa & Rojjanasrirat, 2011:268).

1.4 RESEARCH QUESTIONS

1. In a South African context: how is adolescent HIV self-management realised?

2. What would be the structure, components and items of an instrument that incorporates the context and realities of adolescent HIV self-management?

1.5 RESEARCH AIM

The aim of the research was to develop an instrument to measure adolescent HIV self-management in the context of the Western Cape, South Africa.

In the context of instrument development, the aim of this study was to develop a normative adolescent HIV self-management measure for adolescents between the ages of 13 and 18 that can be used as a screening tool to identify adolescents who need assistance with SM, and the aspects of SM they need assistance with (Foxcroft & Roodt, 2009:67).

1.6 RESEARCH OBJECTIVES

The objectives were to:

1. Explore the realisation of adolescent HIV self-management from the perspectives of adolescents, caregivers and healthcare workers in a South African context.

2. Identify items for inclusion in an instrument to measure self-management in adolescents living with HIV based on the findings of objective one, known self-management models/frameworks, other similar instruments and a literature review.

3. Design and pilot test the instrument.

4. Perform item analysis and determine the validity and reliability of the developed instrument.

1.7 CONCEPTUAL AND THEORETICAL UNDERPINNINGS

Several concepts and theories such as health and well-being, adolescent development, Ecological Systems Theory and Self-Management Theory underpin the study and are discussed briefly.

1.7.1 HEALTH AND WELL-BEING

Health and well-being is a central concept in this study since self-management of a chronic illness is focused at ensuring the health and well-being of the individual. This means that health and well-being is an outcome of self-management behaviours.

Health is the ability to adapt and self-manage in the physical, mental and social domains (Huber et al., 2011:343). The ability to adapt and self-manage is manifested in the *physical* domain as protective responses towards restoring an adapted equilibrium when confronted with physiological stress. Within the *mental* domain it is evident in the individual's ability to comprehend and derive meaning from a difficult situation which may then translate to making use of *social* opportunities dispite limitations (Huber et al., 2011:343). This definition of health corresponds with Smith and Liehr's (2008:3) notion that the term 'healing' and 'health' comes from the same etymological origin meaning 'whole'. 'Healing' in the context of nursing care captures a dynamic meaning that 'health' lacks; healing implying a process of changing and evolving. Nursing care assists the human being with the processes that support relationships, integration and transformation.

Health and well-being in adolescents is subjectively assessed using patient-reported measures such as health-related quality of life (HRQOL). These include dimensions covering physical and psychological well-being, moods and emotions, self-perception, autonomy, parent relations, social support and school environment (Ravens-Sieberer, Herdman, Devine, Otto, Bullinger, et al., 2013:791). A study conducted in the Netherlands by Van Staa (2012:282) found that there was substantial agreement between parents and adolescents regarding HRQOL among adolescents living with a chronic illness. However, parents tended to rate the HRQOL of adolescents lower. She recommended that the focus of measurements should therefore be on the adolescents' perceptions of HRQOL.

1.7.2 ADOLESCENT DEVELOPMENT

The self-management skills of the individual is influenced by their developmental stage. Aspects of adolescent development is therefore briefly discussed here and a further explanation of how it may influence self-management is provided in chapter 2.

Adolescence begins with the onset of puberty and is characterised by physical changes, cognitive and emotional advancement, sexual awakening, and increased sensitivity to relationships with peers (Newman & Newman, 2012:336).

During adolescence physical maturation typically includes a height spurt, appearance of secondary sex characteristics, increased muscle strength and redistribution of body weight. Brain changes occur that gradually improve the regulation of emotion, impulse control and judgement. There is well-documented evidence that development can be variable causing biological diversity amongst adolescents of the same peer group, especially between girls and boys (Newman & Newman, 2012:337; WHO, 2010:14). Early maturation among adolescents has been associated with greater risk of antisocial behaviours, alcohol and drug use and early sexual activity likely due to friendships with older peers (Steinberg & Morris, 2001:90). The

degree to which the physical appearance of the adolescent matches the social and cultural norms influences their self-esteem. This may be a particular concern for perinatally HIV-infected adolescents who have delayed puberty and growth stunting (Lowenthal et al., 2016:6).

Adolescents' mental activity is characterised by an increased ability to engage in abstract, critical and reflective thought involving several dimensions (Newman & Newman, 2012:353; WHO, 2010:14). Jean Piaget coined these complex cognitive capabilities 'formal operations' (Piaget, 1970 in Newman & Newman, 2012:354). Formal operations include conceptual skills such as the ability to think about changes that come with time, solve problems and forsee consequences of actions (Newman & Newman, 2012:353; WHO, 2010:14). The development of formal operational thought can be facililtated by experiences of functioning in a variety of roles (e.g. daughter, friend, student) and engaging with a heterogenous peer group. The school curriculum further supports the development of formal operations provided that learning takes place in a cognitively stimulating way. Formal operations are also influenced by other areas of development such as emotions, sexual drive and the need for social acceptance (Newman & Newman, 2012:356). Therefore, adolescents can revert back to concrete and egocentric thinking when under stress, especially during early and middle adolescence (WHO, 2010:16). Cognitive processes in navigating social relationships develops throughout adolescence. Changes in the social environment, heighted social sensitivity and increased executive functions (e.g. reasoning and problem solving) interact to influence the behaviour of adolescents (Blakemore & Mills, 2014:187). Shortfalls in neurocognitive functions are associated with poorer chronic illness self-management (Lansing & Berg, 2014:1093)

Adolescence may be characterised by emotional variability, moodines and emotional outbursts. Emotions can include anxiety, shame, embarrassment, guilt, shyness, depression and anger (Newman & Newman, 2012:359). Some emotional and behavioural problems originate in earlier periods due to, for example, psycological stress suffered over a period of time or can be due to contexual/environmental influences (Steinberg & Morris, 2001:86). Adolescents who live with HIV may be particularly emotionally vulnerable (Lowenthal et al. 2014:8,9). HIV-positive youth experience behavioural and emotional problems, including psychiatric disorders that may exceed that of the general population (Mellins & Malee, 2013:1).

Socially, adolescents start to separate from their parents and family, spend more time away from home and affiliate with their peers (Newman & Newman, 2012:367). However, research has shown that the increasingly important role of peer relationships may occur alongside continued supportive relationships and emotional attachment to family members. For example, adolescents may demonstrate independence when making decisions about friends, but may want their parents' support and understanding in difficult or serious situations

(Newman & Newman, 2012:369). Further, family support has been found to reduce the practice of risk behaviours such as multiple sexual relationships amongst HIV-positive adolescents (Mhalu, Leyna & Mmbaga, 2013:5).

Social relationships change from being primarily family-based, to a wider network of peers and other individuals in the community and social media (WHO, 2010:14; Jones, Vaterlaus, Jackson & Morril, 2014:54). Peer influences can either influence an adolescent negatively or positively. Susceptibility to peer inflIuence is affected by age, personality, socialistion history and perceptions of peers (Steinberg & Morris, 2001:93). Support and conflict within friendships may enhance or impede psychosocial development (Jones et al., 2014:64). The social competencies of adolescents such as initiating interaction, self-disclosure and support increase throughout adolescence and are related to the quality of their friendships. In later adolescence, decisions are less influenced by peers, with preference for individual relationships (WHO, 2010:16). With sexual maturation, adolescents are likely to engage in friendships with the opposite sex and romantic relationships (Steinberg & Morrs, 2001:95).

Some households are parentless, especially in the South African context where there is a high HIV burden and many children are orphaned. Parental roles in such cases are fulfilled by caregivers for example, family members or adoptive parents. I therefore refer to the word 'caregiver' that may be a biological parent or a person looking after an adolescent. Caregiver-adolescent conflicts (especially conflict with mothers) increase during adolescence and as a consequence, they report less closeness and time spent with caregivers (Steinberg & Morris, 2001:88; Newman & Newman, 2012:369). This may influence the self-management support adolescents receive from caregivers. In the context of HIV, caregivers may continue to be an important support structure for adolescents since they are unlikely to disclose their HIV status to friends. Once adolescents mature, they are likely to engage in a more egalitarian relationship with their caregivers, where adolescents are provided with more autonomy and influence in family decision-making (Steinberg & Morris, 2001:89; WHO, 2010:14). Parenting styles appear to play a role in adolescent outcomes. An authoratitive (warm/responsive and firm) parenting style is associated with better adjustment, school performance and psychosocial maturity (Steinberg & Morris, 2001:88).

Psychological changes in adolescents may be due to age, pubertal status and social changes associated with age, for example how parents, teachers, siblings and peers respond to physical appearance changes. Furthermore, adolescents have a need to explore, which may result in risk-taking behaviours such as alcohol or drug abuse or unsafe sex (Newman & Newman, 2012:338,379). This exploration together with their sense of invulnerability may influence self-management behaviours. In South Africa, 12% of adolescents reported to initiate alcohol use before the age of 13. Binge-drinking rates vary between 17.9% and 33.5%

and an significant increase in female binge-drinking rates have been reported (Morojele & Ramsoomar, 2016:551). In a United States study, 34% of HIV-infected youth reported regular tobacco use, 28% used dagga (cannabis) weekly or daily and 22% used alcohol weekly or daily (Fernández, Huszti, Wilson, Kahana, Nichols, et al., 2015:921). Steinberg and Morris (2001:86), however, confirms occasional experimentation is more common than permanent patterns of risky behaviours and most problems experienced by adolescents are fairly temporal. Even if these behaviours are transitory, it may significantly affect HIV-positive adolescents' adherence to treatment, their treatment outcomes and increases the risk of HIV transmission.

Some behaviour changes during adolescence are due to changes in hormone production associated with levels of arousal, emotionality and sexual drives (Newman & Newman, 2012:337). During later adolescence, gender identity and sexual orientation is developed (Newman & Newman, 2012:347). Sexual identity formation during adolescence is shaped by cultural and societal norms and some adolescents may engage in sexual relationships early, for example, due to the value placed on having children (Lowenthal et al., 2014:10). Worldwide the average age of sexual debut is 17.7 years (WHO, 2010:14). The South African National HIV prevalence, Incidence and Behaviour Survey found that 10.7% of adolescents aged 15-24 reported having sex for the first time before the age of 15 (Shisana, Rehle, Simbayi, Zuma, Jooste, et al., 2014:33). Of those adolescents who were sexually active, 12.6% reported having more than one sexual partner in the last 12 months (Shisana et al., 2014:33). Despite knowledge of their HIV status, some adolescents engage in risky behaviour. They are having sex with or without condoms in both committed or casual relationships (Weintraub, Mellins, Warne, Dolezal, Elkington, et al., 2017:136). A study in Tanzania found that 40% of young HIV-positive males and 37.5% of females reported unprotected sex; 50% did not know the HIV status of their partners and a modest proportion engaged in multiple sexual partnerships. Alcohol use was also associated with less condom use (Mhalu et al., 2013:4). Early initiation of sex, coupled with non-disclosure to partners, increases the risk of HIV transmission.

Biological, cognitive and social changes stimute adolescents to think and reflect about the kind of individual they want to be (Crocetti, 2017:145). Adolescence is a period where an individual explores the self, discovers who they are and their place in the social world (Steinberg & Morris, 2001:91). Erik Erickson describes the period of adolescence as a developmental conflict between identity formation versus role confusion. Due to changing physical, cognitive and social factors, most adolescents experience some form of role confusion but resolve these issues and develop a sense of identity, social interaction, affiliation and moral values (Sokol, 2009:2). Marcia's identity paradigm (Marcia, 1966 in Crocetti, 2017:145) adds two dimensions to coping with the identify crisis, namely, exploration and commitment, which could lead to

four identity statuses: foreclosure, achievement, moratorium and diffusion. More recently, in the process of describing how identity is formed, the three factor identity model was developed that depicts the process by which an individual forms and changes their identity over time (Crocetti, 2017:146). Crocetti (2017:148) asserts that although identity development is a developmental task across one's lifespan, it becomes urgent in adolescence. Being able to find a stable identity is strongly connected with adolescents' psychosocial functioning and well-being.

Adolescents become more aware of personal beliefs and standards and may question religious and political ideologies held by caregivers. Since they are in the process of developing their self-concept, they may describe themselves in ways that are contradictory, for example, shy with friends but outgoing at home; their self-concept may also differ across contexts (Steinberg & Morris, 2001:92). Decisions about morality are driven by social approval and conformity. They may want to obey instructions from healthcare workers or parents so that they may be thought of as being 'good' but conversely want to appear 'normal' to their peers (Lowenthal et al., 2014:9). This reasoning may change in the later stages of adolescence where moral reasoning moves beyond the need for individual approval.

Newman and Newman (2012:367,370) asserts that a positive group identity fosters a meaningful connection to society; the psychosocial crisis of adolescence being group identity versus alienation (absence of social support or meaningful social connection). A strong ethnic and racial identity is further associated with higher self-efficacy and self-esteem and are central to the normative development of youth of color (Umaña-Taylor, Quintana, Lee, Cross, Rivas-Drake et al. 2014:21). For adolescents living in a mixed cultural background, multiculturalism is associated with better psychological adjustment (Steinberg & Morris, 2001:92).

The developmental level of a person determines how interactions take place and to what extent these influence self-management. There is a substantial gap in the understanding of self-management across the developmental stages (Ryan & Sawin, 2009:220). Further, it is not known how living with a chronic condition such as HIV can impact on the process of personal and group identity formation. The developmental stage of adolescents with HIV may vary since HIV can impact on their general development causing delay of puberty, growth stunting and shortfalls in cognitive functioning such as memory, mental processing and language abilities (Lowenthal et al., 2014:6). This may further influence the ability of the adolescent to accurately perceive their own self-management. An adolescents' level of development therefore needs to be taken into consideration when assessing self-management from the perspective of the adolescent.

1.7.3 ECOLOGICAL SYSTEMS THEORY

There are several contextual factors that may influence adolescent HIV self-management. These contexual factors are discussed using the Ecological Systems Theory as a framework in chapter 2.

The Ecological Systems Theory of Bronfenbrenner (1979) emphasises the contextual influences of the ecological systems in which a child/adolescent grows. These systems range from the microsystem, which refers to the relationship between the child and the immediate environment (school, family, peers, health services etc.) to the macrosystem, which refers to the culture, body of knowledge and societal norms (Bronfenbrenner, 1994:37). Immediate interactions, also called proximal processes, between the individual and their family, school and the health services (microsystem) and the interactions between the settings in which the individual finds him/herself (mesosystem), influences their development. Adolescence in particular is a period with dramatic changes in both the content and context of development (Steinberg & Morris, 2001:84). It is therefore fitting to consider the context in which the adolescent finds him or herself when exploring self-management.

In Bronfenbrenner's later work (Bioecological Model), he theorised that proximal processes may be the most powerful predictor of human development and that healthy proximal interactions may buffer the potential negative impact of macrosystem factors (Rosa & Tudge, 2013:251). However, Steinberg and Morris (2001:89) argue that adolescent development is influenced by various genetic, familial and non-familial factors, resulting in a complex socialisaton process. Proximal processes or immediate interactions with caregivers may be influenced by increased conflict and the adolescent's need for autonomy and separation. Meaningful interactions with peers and with healthcare workers start to be increasingly important during adolescence. Living with a chronic disease such as HIV, which may affect more than one family member, causes a unique dynamic of interactions between family members.

There is a dynamic interaction between the levels or systems. The equilibrium between these systems ultimately defines the overall health experience (Mburu, Ram, Oxenham, Haamujpompa, Iorpenda & Ferguason, 2014:11) or in the context of this study, adolescent HIV self-management. In this study, an integrated socio-ecological approach is used to explore adolescent HIV self-mangement. It is recognised that self-management extends beyond the individual to their socio-cultural environment and that adolescents are connected to their social ecosystem.

Self-management processes and behaviours result from interactions between the microsystem and mesosystem and can be influenced by various factors in each of the systems (Modi et al., 2012:478).

1.7.4 SELF-MANAGEMENT THEORY

There are several self-management theories and frameworks that will be further discussed in chapter 2. The self-management theory that was used as a framework and conceptual basis for this study is the Individual and Family Self-Management Theory (IFSMT) of Ryan and Sawin (2009:217). It is a middle-range descriptive theory that proposes that SM is a complex phenomenon consisting of three dimentions namely context, process and outcomes (Figure 1.1). Middle range theories consists of concepts and suggested relationships among concepts focused on a limited dimension of reality (Smith & Liehr, 2008:6). This theory was chosen since it meaningfully captured the relationships between contexual factors, SM processes and SM outcomes. It could therefore be used to identify variables to test the validity of the developed adolescent HIV self-management instrument.

Individuals and families engage in self-management of chronic conditions by deliberately performing a set of learned behaviours that becomes integrated into their lifestyle. The IFSMT integrates individual and family self-management and supports the notion that caregivers are actively involved in the SM of adolescents and that these adolescents may also impact the SM of their caregivers (who may also be on ART).

The IFSMT is appropriate for this study since adolescents, in most cases, still rely on their caregivers to assist them and it acknowledges that SM is fluid and the roles of family members may change over time, for example when adolescents transition to adult care. This theory was used as the primary basis for this study. Further, due to the inclusion of contextual factors, SM processes and SM outcomes, it could be used to test the validity of the developed measure. The aspects thereof are illustrated in Figure 1.1 and are briefly discussed in the following paragraphs, with a more in-depth discussion following in chapter two.

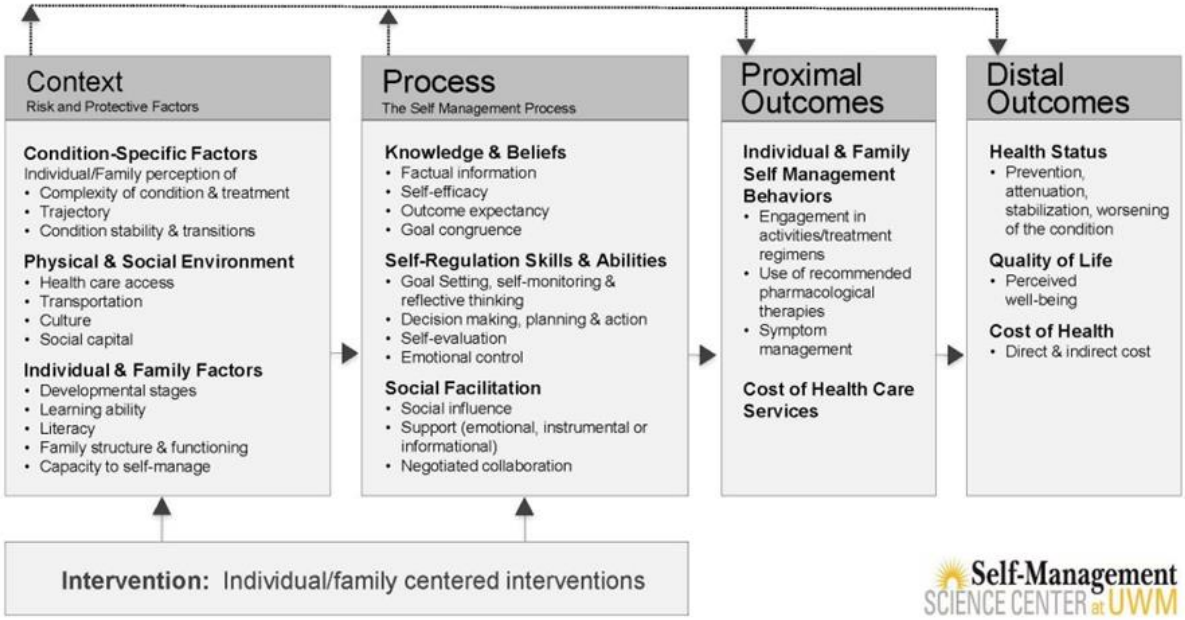

Figure 1.1 Individual and Family Self-Managemetn Theory (Ryan & Sawin, 2009; 2014)

Factors in the *context* dimension influences individual and family engagement in self-management processes, but also directly influences SM outcomes (Figure 1.1). Several risk and protective factors influence SM: health status, individual factors, family factors and environmental factors. Each of these factors have sub-categories, for example, the sub-categories of health status are disease severity and the characteristics of the treatment regimen.

SM *processes* are based on the dynamic interaction between: i) condition specific knowledge and beliefs; ii) acquisition and application of self-regulation skills and abilities and iii) social facilitation and negotiation. The focus of this study was to explore, describe and then measure these SM processes in adolescents living with HIV in a South African context.

Proximal outcomes include disease-specific SM behaviours such as treatment adherence and *distal outcomes* include health status, perceived quality of life and well-being.

The interaction among the concepts can be complex. Factors in the context dimension may affect the individual's and family's ability to engage in the process dimension and may also directly impact on outcomes. Concepts in the process dimension are related to the context and outcome dimensions and are interrelated. For example, the process concepts Knowledge and beliefs, Social facilitation and Self-regulation are interrelated. Knowledgeable engagement in supported self-regulated behaviours leads to engagement in SM behaviours/proximal outcomes e.g. adherence. Achievement of proximal outcomes may in part cause distal outcomes such as health-related quality of life (Ryan & Sawin, 2009:10-11).

Ryan and Sawin (2009:11) further states that this theory may be used as a situation-specific theory and should be tested to determine which concepts mediate/moderate SM and if the concepts are applicable across sub-populations, conditions and contexts.

1.8 PHILOSOPHICAL FRAMEWORK

The particular worldview or paradigm of the researcher may influence the actions taken in every step of the research process. The paradigm in which the research is located influences the meaning the researcher attaches to human beings, human-environment interaction, health and caring (Smith & Liehr, 2008:6). The theoretical underpinnings of the study are located in both the interactive-integrative and unitary-transformative paradigms. The unitary-transformative paradigm holds that subjective experience reflects the whole human-environment pattern and the complex organisation thereof. The interactive-integrative paradigm takes into account contextual, subjective and multidimensional relationships (Smith & Liehr, 2008:6). The researcher used subjective experiences to pattern adolescent HIV self-management and further continued to explore interrelationships between the parts/concepts of self-management while keeping in mind the probabilistic nature of change.

The fundamental belief of the researcher is that of pragmatism, which means that the most appropriate research traditions or methods should be used to address the research questions (Richie, Lewis, McNauthton Nichols & Ormston, 2014:22). This means combining different research methods such as the interpretive and post-positivist standpoints (Wahyuni, 2012:70; Creswell, Klassen, Plano Clark & Smith, 2011:5).

The researcher investigated the research objectives over several phases and used multiple worldviews that shifted from one phase to the next. In the first and second phase of the study, the researcher worked from interpretivist principles, valuing deeper meanings and multiple viewpoints. During the third and fourth phases of the study, the assumptions shifted to that of post-positivism in order to guide the need to identify items for the instrument and to measure variables and statistical trends (Teddlie & Tashakkori, 2009:87). The philosophical positions of the approaches and research designs used in the study phases are discussed below.

1.8.1 Ontological position

The two ontological positons used in this study are idealism, that is, external reality is dependent on a person's beliefs and understandings; and realism, that is, reality exists independent of our beliefs and understanding (Ritchie et al., 2014:4).

During the first phase of the study, the ontological perspective was collective/contextual idealism where the researcher aimed to conceptualise the meaning of self-management as constructed by adolescents, caregivers and healthcare workers.

The identification of items for inclusion in a measurement instrument and thereafter, the measurement of self-management, were based on cautious realism. The researcher was aware that reality can be known approximately or imperfectly rather than accurately (Ritchie et al., 2014:5). The true construct of self-management is complex and may never be measured accurately, but various methods were employed to improve the accuracy of the measurement instrument.

1.8.2 Epistemological position

The researcher primarily used abductive (describing data using researcher-determined categories) logic during the first phase of the study and used deductive logic to test hypotheses in the fourth study phase (Richie et al., 2014:6).

The relationship of the researcher to the participants or the data was that of empathic neutrality, by acknowledging that the researcher's own assumptions may influence the data and therefore these assumptions, biases and values were made transparent (Ritchie et al., 2014:8). The researcher was reflexive about her influence on the research process. This was illustrated throughout the study in reflecting on how the researcher's own biases may have influenced the interpretation of the study findings as well as reflecting on the instrument development process as a whole.

Lastly, the researcher acknowledges intersubjectivity, meaning that truth or reality is not absolute. The researcher employed literature control, validity and reliability measures to ensure that the study findings approximate the true reality.

1.8.3 Methodological position

Methodologically, the researcher employed both interpretivism and post-positivism (Richie et al., 2014:10,12).

During the first phase of the study, the researcher employed Interpretive Phenomenology. Emphasis was placed on understanding the participants' perspectives in the context of the conditions and circumstances of their lives. This assisted in conceptualising the concept of adolescent HIV self-management from the perspectives of participants in a South African context. Participant accounts were interpreted in the light of what is known about the concept (through theories and previous studies), the participants' context, the researcher's own experience and further feedback from the participants using the hermeneutic process. During the identification of items for inclusion in the instrument and relating these items to theoretical concepts, the researcher illustrated how interpretations were embedded in the data provided by the study participants.

In order to validate the developed adolescent HIV self-management instrument, a post-positivistic approach was used. This means that reality can only be known approximately and that null hypotheses can be rejected or tentatively confirmed (Ritchie et al., 2014:10). Statistical measures such as item analysis, reliability testing, factor analysis and hypothesis testing were used to psychometrically test the developed instrument.

1.9 ASSUMPTIONS

The researcher's assumptions influence the instrument development process and should be explicitly revealed and reflected upon to ensure the integrity of the research (Onwuegbuzie, Bustamante & Nelson, 2010:61). The perspective of the researcher regarding adolescent HIV self-management is one of unconditional positive regard, namely the researcher assumes that an adolescent is capable of self-management, with the needed support from caregivers and healthcare workers. Although adolescents are viewed by many as 'difficult' and 'complex' to manage, the researcher at the inception of the study believed that adolescents have the capacity to make positive autonomous decisions about their own health. The researcher, however, acknowledges that various complex individual and situational factors may influence the capacity of the adolescent to make such autonomous decisions. In addition to this, the valuation of adolescents' own self-management may not be accurate.

Another assumption of the researcher was that study participants provided honest and truthful responses during interviews or when completing questionnaires. Furthermore, it was assumed that the established instruments used to test the validity of the developed instrument yielded reliable and valid data on the study sample. Lastly, the assumption was that adolescents aged 13-18 would have a reading literacy at a grade 6 level in their home language (English, Afrikaans or isiXhosa).

The Individual and Family Self-Management Theory used to underpin this study also have several assumptions as described by Ryan and Sawin (2009:225):

- Persons engage in behaviours for reasons that may not be directly related to improving their health.
- Individual SM ability and SM behaviours are influenced by several contextual factors.
- The primary responsibility or control for SM lies with the individual or family.
- SM processes are iterative and requires time, repetition and reflection.
- Person/family centred approaches to healthcare fosters SM.
- Persons engaging in SM behaviours may or may not collaborate with healthcare providers.

The researcher critically reflected on these assumptions throughout the research process.

1.10 STUDY SETTING AND TARGET POPULATION

The study was conducted in the Cape Town Metropolitan district, an urban community in the Western Cape, South Africa (Figure 1.2). The community predominantly falls in a low socio-economic category and is largely Coloured and Black. The official languages in the Cape Metropolitan district are English, Afrikaans and isiXhosa.

Figure 1.2 Geographical presentation of the study setting (Districts of South Africa, 2016)

At the onset of the study (2015), there were 7 976 children under the age of 15 on ART in the six health districts of the Western Cape compared to 175 854 adults. Of the total of children under that age of 15 on ART, 5 738 (71.9%) received care in the Cape Town Metropolitan district (Western Cape Department of Health, 2015). As with most other countries (UNICEF, 2016:37), the South African Department of Health (DoH) does not report routine disaggregate data on the number of adolescents on ART, but the researcher requested the data from the DoH for the fourth phase of the study during December 2015. The data at the time, indicated that 1 457 adolescents between the ages of 13 and 18 received care at primary health care clinics in the Cape Metropole (Western Cape Department of Health, 2015).

The Cape Town Metropolitan district was the most accessible district for the researcher and the district with the highest number of children and adolescents on ART in the Western Cape. Focusing on an urban setting provided an opportunity to collect in-depth data in order to accurately conceptualise adolescent HIV self-management from the perspectives of adolescents within this age range, caregivers and healthcare workers, irrespective of their language preferences. The majority of people in South Africa reside in major urban centres and the cultural and socio-economic diversity in urban settings also provided the opportunity to identify a wide range of issues related to adolescent HIV self-management. The usefulness

of the instrument that resulted from this study may therefore be enhanced by first developing and validating it in an urban setting.

For the purpose of this study, male and female adolescents aged 13 to 18 (secondary school aged) who attended HIV services at public healthcare clinics were included. The age group was chosen based on evidence that non-adherence problems and virological failure are more prevalent in adolescents aged 13 and above (Usitalo, Leister, Tassiopoulos, Allison, Malee, et al., 2014: 112). This age grouping was also common for adolescent/adult services in the study setting.

In South Africa, adolescents are cared for in paediatric services until the age of 12 or 13. The researcher observed that some clinics have adolescent clubs/groups where adolescents attended for treatment at different times to children or adults. These clubs were used to discuss certain topics about HIV and adolescents were recruited into the clubs from the age of 12 or 13, usually following full disclosure of their HIV status. By the age of 13 most would therefore know their HIV status. Some of these adolescents would remain in the group until the age of 17 or 18, after which they would have to be transferred to adult care. Young persons aged 18 and above are not children anymore and are considered fully capable of making independent decisions about their health without the assistance of parents or legal guardians (Republic of South Africa, 2005:12).

1.11 OVERVIEW OF RESEARCH DESIGN AND METHODS

A mixed method multiphase (exploratory sequential) design was used. This design is commonly referred to as an instrument development design (Teddlie & Tashakkori, 2009:86; Creswell et al., 2011:13). Mixing approaches optimised the study sample (participant enrichment) and provided instrument fidelity (maximised the appropriateness and/or utility of the instrument) (Onwuegbuzie, Bustamante & Nelson, 2010:57). The four phases of the study are summarised in Figure 1.3 and discussed in more detail in chapter 3.

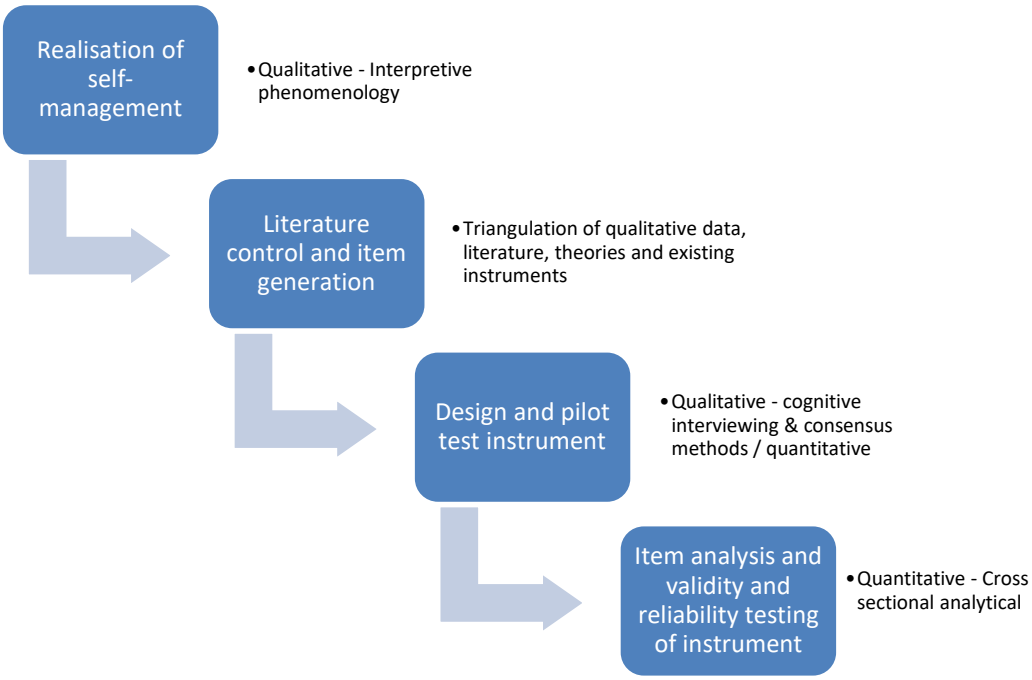

Figure 1.3 Four phases of the study

1.12 OPERATIONAL DEFINITIONS

In this study an **adolescent living with HIV** is a child between the ages of 13 and 18 who is HIV positive (irrespective of how they acquired HIV – perinatally or behaviourally), who may or may not yet be on ART.

Caregivers in this study may include one or both biological parents or a legal guardian such as a family member or foster parent. These caregivers assist adolescents with self-management.

Context in this study includes the various systems the adolescent develops in, for example, the microsystem, mesosystem and macro system (Bronfenbrenner, 1994:37). It incorporates the consideration of the circumstances of each adolescent in which the practice of self-management can be understood.

Culture means the shared beliefs and social habits of a group of people that is part of their everyday existence. Elements of culture forms part of the context in which self-management is practiced (Grey, Knafl & McCorkle, 2006:278).

Development in this study refers to human development on a physical, cognitive and social level. It is acknowledged that the developmental stage of the adolescent may influence their self-management skills (Ryan & Sawin, 2009:220).

Healthcare workers in this study include all the persons involved in the care of the adolescent and included doctors, nurses and lay counsellors.

Psychometric evaluation/testing is concerned with determining the psychometric properties, such as validity and reliability, of an instrument. In this study it included statistical procedures such as factor analysis and coefficient alpha (De Vellis, 2012:104)

Self-management in this study is the behaviours or processes that adolescents engage in (individually or in collaboration with caregivers or health workers) that will contribute to their health, well-being and control of their chronic condition (HIV). This concept will be further explored and contextualised in the South-African, and specifically the Western Cape setting, throughout this study.

1.13 DELIMITATIONS

This study was specifically limited to adolescents between the ages of 13 and 18 years who were accessing HIV care at health facilities in the Cape Town Metropolitan district of the Western Cape, South Africa.

1.14 DURATION OF THE STUDY

The study was approved by the Stellenbosch University Health Research Ethics committee on 20 May 2015 (Appendix 1). Data collection for phase one commenced in July 2015 following provincial, municipality and institutional permission (Appendix 2). Data collection was completed on 4 August 2017 and the thesis submitted for evaluation in October 2017 (Table 1.1).

Table 1.1 Duration of the study

	Year 1 (2015)				Year 2 (2016)				Year 3 (2017)			
Quarters	1	2	3	4	1	2	3	4	1	2	3	4
Registration, ethics and provincial approval												
Phase 1												
Phase 2												
Phase 3												
Phase 4												
Write up, editing and submission												

1.15 CHAPTER OUTLINE

The dissertation is organised according to the following chapters:

Chapter 1: Foundation and background to the study

Chapter 2: Literature review

Chapter 3: Research methodology

Chapter 4: Realisation of adolescent HIV self-management

Chapter 5: Discussion, literature control and item generation

Chapter 6: Instrument design and pilot testing

Chapter 7: Item analysis, validity and reliability testing of the instrument

Chapter 8: Discussion, key findings and recommendations

1.16 SIGNIFICANCE OF THE STUDY

There is limited scientific evidence regarding self-management of HIV in adolescents, particularly in an African setting with its unique challenges. This study reveals new insights into the components of adolescent HIV self-management in countries with limited healthcare resources such as South Africa that may help healthcare providers to tailor interventions to meet the needs of adolescents. In addition, fostering self-management behaviours in adolescents as they transition to adulthood may improve their long-term outcomes. The product of the research process is a research-based operational definition for self-management, a preliminary adolescent HIV self-management framework that can serve as a conceptual base for further research and a new instrument, which could be used to measure the effectiveness of adolescent self-management interventions. The instrument also has the potential to be used as a care tool.

Evidence regarding HIV self-management for both adolescents and adults in South African is limited and will be very valuable since the country has the largest ART programme globally (3.9 million persons on ART at the end of August 2017). The findings from this study provides a theoretical base and framework for self-management for this group that serves as a platform for further research into self-management in other groups such as adults living with HIV or other chronic diseases.

1.17 SUMMARY

In this chapter, an overview of the study background, rationale, aims and objectives is given. The study followed an exploratory sequential mixed-method design to develop and validate an instrument to measure adolescent HIV self-management. The research methodology is discussed further in chapter 3 of the dissertation and an in-depth discussion of the literature related to adolescent HIV self-management is provided in chapter 2.

1.18 CONCLUSION

HIV/AIDS is the leading cause of mortality amongst adolescents in Africa, yet there is a paucity of research literature on adolescent HIV self-management in an African context. Various

theories and frameworks have been developed to clarify the concept of self-management, but it is still unclear how adolescent HIV self-management is realised in a South African context, amidst the high prevalence of poverty, community violence, child abuse, alcohol and drug use. Repeated assertions in the literature indicate that high self-management will have a positive effect on treatment adherence and overall outcomes for adolescents living with HIV. Understanding adolescent HIV self-management, including the components and measurement thereof may therefore make a unique contribution to the management of adolescents living with HIV in the South African and larger African context, with the possible benefit of improving their general well-being and development.

CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

The aim of the literature review was to identify relevant theoretical or conceptual frameworks and other literature related to the construct in order to conceptualise self-management (Onwuegbuzie et al., 2010:63). The literature provides an etic perspective of the construct under study that will later be supplemented with the emic perspectives (participant views).

There is a paucity of research exploring self-management (SM) in adolescents with HIV. However, there is a broader body of literature that has explored SM in adolescents with other chronic diseases and SM in adults living with HIV. There is also a plethora of literature on treatment adherence in children, adolescents and adults.

The concepts of adherence and SM are often used interchangeably. However, in this thesis they are separated. Self-management broadly focuses on all interactions and processes involved in managing a chronic condition while adherence places emphasis on the extent to which a person's behaviour coincides with medical or health advice, with a particular focus on treatment-taking behaviours (Modi et al., 2012:480). Ryan and Sawin (2009:219) refer to adherence as a SM behaviour that is a proximal outcome of SM processes.

In this chapter, the literature related to adolescent HIV SM is explored and discussed narratively.

2.2 ELECTING AND REVIEWING THE LITERATURE

Databases such as PubMed (MEDLINE), CINAHL and Google Scholar were searched for studies on adolescents, HIV and self-management. Key words and their MESH terms included: adolescents, teens or young people; HIV or AIDS; self-management, self-care or adherence; and quality of life, health outcomes or development. Quantitative and qualitative published studies in English were reviewed. Relevant conference abstracts, theses, dissertations, international- and national guidelines were also reviewed. This review continued throughout the research process.

2.3 ADOLESCENTS LIVING WITH HIV: A VULNERABLE POPULATION?

Adolescents living with HIV can be considered as a vulnerable population group with diverse needs (Santos Cruz, Hance, Korelitz, Aguilar & Byrne, et al., 2011:165; Agwu & Fairlie, 2013:185). As explained in chapter 1, the developmental period of adolescence can be complex and is characterised by physical, cognitive, emotional and social changes (Newman

& Newman, 2012:336). In particular, the significant physiological and psychological evolution that occurs during adolescence places them at risk for non-adherent and risky behaviours. Adolescents may also encounter numerous barriers to access services (UNICEF, 2013a:3). The health and well-being of adolescents living with HIV are affected by a number of issues such as delayed growth and puberty (Majaliwa, Mohn & Chiarelli, 2009:85), complications of ART (Arpadi, Shiau, Strehlau, Martens & Patel, et al., 2013:258), poor neurocognitive functioning (Souza, Santos, Valentini, Silva & Falbo, 2010:421) and psychiatric problems (Mellins & Marlee, 2013:1). In addition, they are faced with numerous social contextual complexities such as parental HIV/AIDS illness and disability, poverty, child abuse, community violence and HIV/AIDS related stigma (Cluver, Orkin, Boyes, Sherr, Makasi & Nikelo, 2013:185). All these factors interplay and affect the health outcomes as well as the general development of adolescents living with HIV.

Although adolescents with HIV are considered to be a vulnerable group, children in many parts of sub-Saharan Africa are trained in a variety of skills and responsibilities from an early age to prepare for difficulties they may face in life (Skovdal & Daniel, 2012:155). Adolescents who live with HIV therefore may have the ability to exercise agency in order to achieve health and well-being dispite several contextual challenges (Skovdal & Daniel, 2012:155). Betancourt, Meyers-Ohki, Charrow and Hansen (2013:22) state in their review on resilience and mental health in children and adolescents affected by HIV/AIDS that there is a need to explore and understand the resources for promoting resilience in HIV-affected families and communities in various contexts. Resilience in itself is a complex phenomenon and the relationship between resilience and SM will be discussed further in section 2.11.

2.4 HISTORICAL PERSPECTIVES ABOUT THE CONCEPT OF SELF-MANAGEMENT

There is an increasing body of literature acknowledging the role of SM in the management of chronic diseases. However, there are various perspectives of SM.

The use of the term self-management, initially based on the writings of Albert Bandura, dates back to the mid-1960's and was used in conjunction with the management of chronically ill children (Lorig & Holman, 2003:1). Lorig and Holman (2003:1) based their definition of self-management on the premise that "one cannot not manage", therefore "the only question is how one manages." They identified several tasks of self-management which was based on the work of Corbin and Straus of 1988, namely "Unending work and care: managing chronic illness at home" – studying patients with chronic conditions. These tasks included medical management; maintaining, changing and creating new meaningful life roles; and dealing with emotional reactions, which alters one's view of the future. In addition, they identified five core

self-management skills: i) problem solving; ii) decision making; iii) resource utilisation; iv) forming patient-heathcareworker partnerships; and v) taking action. According to Corbin and Straus (1988:11), managing a chronic illness at home is a type of work which is divided among the people living with the illness, family members, friends, healthcare professionals and others. Who does what work and when, depends on the type of work to be done, the skill and knowledge level needed for its performance, the physical and mental ability of the available people and other variables such as variations in mood, fatigue level, convenience, and boredom. Self-management skills or tasks are often used to develop self-management education programmes. These programmes are focused on increasing patient self-efficacy to perform self-managment skills and tasks, which leads to improved health outcomes (Lorig & Holman, 2003:4).

Sattoe, Bal, Roelofs, Bal, Miedema and Van Staa (2015:709) investigated the theoretical base for self-management interventions amongst young people living with chronic conditions and found that Social Learning Theory and Cognitive Behavioural Theory was the most often used theoretical frameworks underpinning interventions. Social Learning Theory and Cognitive Behavioural Theory, holds that there is a reciprocal relationship between thoughts and cognitive processes, the environment (social and physical) and behaviours. Cognitive processes such as self-regulation (for example, goal-setting, self-monitoring, reflective thinking) enhances self-efficacy and this in turn leads to SM behaviours (Ryan & Sawin, 2009:5). Self-efficacy is a central concept in self-management which means the confidence to carry out behaviours necessary to reach desired goals (Bodenheimer, Lorig, Holman & Grumbach, 2002:2496).

Systems Theory has also influenced the development of the concept SM. SM is multidimensional and can be conceptualised on an individual or a family level (Ryan & Sawin, 2009:2). Recently, the meaning of SM has been combined to include individuals and families incorporating systems theory whereby a change in one system affects another system. The paediatric self-management model developed by Modi et al. (2012:476) enunciates that individual-, family-, community- and health care system-level factors impacts SM through cognitive, emotional and social processes. This resonates with the Ecological Systems Theory of Urie Bronfenbrenner discussed in chapter 1.

The Chronic Care Model (CCM) of Wagner is described as “a synthesis of evidence-based system changes intended as a guide to quality improvement and disease management activities.” The CCM proposes that the healthcare system is part of the larger community and that the organisation and practices should be geared towards productive interactions between patients and providers leading to improved outcomes (Wagner, Austin, Davis, Hindmarsh, Schaefer & Bonomi, 2001:69). Theoretical and empirical research has shifted from a patient’s

knowledge about their disease towards their confidence and skills to manage their condition (Wagner et al., 2001:70). Components of the CCM include: community resources and policies; healthcare organisations; SM support; delivery system design (organisation of the facility and types of staff available); decision support (guidelines and support for healthcare providers) and clinical information systems (type of record system and use of that system). In this model, SM support consists of assisting patients to develop skills to manage their chronic condition such as improving their self-efficacy, provision of equipment if needed and regular contact with the healthcare provider to assess progress. Bodenheimer (2003:63) reviewed the effects of several interventions using the CCM components and reported that clinical outcomes improve when more than one of the CCM components are used together. Of the 20 studies that involved patient SM support as a component, 19 showed improved outcomes.

In the context of chronic disease, patient SM is an inescapable fact (Bodenheimer et al., 2002:2496). Patients decide on a daily basis what they are going to eat, whether they will change their behaviours or whether they will take prescribed treatment. SM is the ability of an individual to manage the physical, social and lifestyle consequences of living with a chronic disease in conjunction with their family, community and healthcare professionals (Sattoe et al., 2015:705). This includes day-to-day decisions and related behaviours that individuals engage in to manage their illness and promote health (Webel et al., 2012:72).

SM can therefore be described as involving processes such as self-regulation and self-efficacy that occurs on an individual and interpersonal/social level, which in turn leads to SM behaviours that are specifically focused on disease management and promoting health.

2.5 THE ROLE OF NURSES IN PROMOTING SELF MANAGEMENT

Traditionally nursing is focused on providing holistic care and follows a biopsychosocial approach to care. Biopsychosocial interventions in essence are person centred and the concepts of self-management and supporting patients to self-manage should be familiar to nurses. Yet, there seems to be a paucity of literature about the views of nurses on patients' SM tasks and their role in supporting patients to self-manage (Been-Dahmen, Dwarswaard, Hazes, Van Staa & Istra, 2015:2834).

Been-Dahmen et al. (2015:2834) explored nurses views on patient SM in the Netherlands. They found that although SM support for patients living with chronic illnesses is seen as one of the core tasks of nurses in outpatient settings, nurses seem to lack sufficient training to provide the support that meets the needs of patients. There seems to be more focus on medical management (adhering to treatment and monitoring symptoms) while overlooking social and emotional tasks of living with a chronic condition and integrating it into daily life.

Further, nurses tend to apply interventions that do not increase the self-efficacy and self-regulation skills of patients.

It therefore seems that nurses must assume new roles and acquire specific competencies in order to support patient SM (Duprez, van Hooft, Swarswaard, Van Staa, van Hecke & Strating, 2016:1381). Emphasis should be placed on nursing competencies needed to encourage patients to take the lead in self-managing their chronic illness.

One model of organising self-management support is the five A's: assess; advise; agree; assist and arrange (Duprez et al., 2016:1382). During the *Assess* phase, nurses need to explore a patient's beliefs and motivation about living with a chronic illness. *Advice* includes providing information about the disease and symptoms. The *Agree* phase requires skills for collaborative goal-setting and in the *Assist* phase, nurses need to enable patients to integrate chronic care into their daily lives. The last phase, *Arrange*, refers to follow-up care. The five A's approach is recommended by WHO (2010:73) as an important part of chronic care for adolescents who live with HIV.

Nurses therefore have a key role to play in enabling patient SM. However, care focused on SM requires specific skills that should be taught to nurses and other healthcare workers if SM support is going to be realised in practice. Interventions for adolescent HIV SM can only be effective if the components of adolescent HIV SM are adequately understood.

2.6 FRAMEWORKS FOR SELF-MANAGEMENT: CHRONIC DISEASES AND HIV

Several authors have identified common SM tasks accross chronic conditions. Sattoe et al., (2015:705) describes three domains of self-management of chronic conditions amongst the youth including medical management (managing symptoms and promoting health), role management (managing the impact of chronic illness on relationships, functioning and life roles) and emotional or identity management (managing emotions commonly experienced). These domains have been previously identified and described by Lorig and Holman (2003:2).

Medical management includes disease specific tasks such as understanding the disease and treatment regimen, dealing with symptoms and self-monitoring of clinical outcomes. General tasks include accessing healthcare and information, communicating with the healthcare provider, setting goals such as reducing risk behaviours and sharing responsibilities within the family (Sattoe et al., 2015:709). Emotional or identity management involves improving self-confidence, self-esteem and self-efficacy. It also involves decreasing negative thoughts, managing anger and decreasing boredom and social isolation. Role management or social participation tasks includes forming friendships and social networks, managing teasing and

bullying, participating in normal social activities such as social media, age appropriate independency, explaining the condition to others, disclosure and setting life goals (Sattoe et al., 2015:709).

According to Sattoe et al. (2015:710), the following six skills can be applied across the medical, emotional and social domains: problem solving, decision making, resource utilization, the formation of a patient-provider relationship, action planning and self-tailoring. These skills are similar to the skills identified by Lorig and Holman (2003:4).

Disease specific knowledge is an important component of medication SM (Barnes Abramowitz, Lagrange, Chandwani, Moschel & Koenig, 2013:314). Barnes et al. (2013:314) studied a sample of American HIV-infected youth aged 13 to 21 and found an average HIV knowledge score of 78.1%, with behaviourally-infected and older youth outperforming perinatally-infected and younger youth. However, few of the participants could explain the concepts of viral load (VL) and CD4 count and only 29.5% of youth knew either their VL or CD4 count. Behaviourally-infected youth may have higher knowledge scores since they assume greater responsbility for their own health care in the absence of other support or because of their own experiences of risky behaviours. Perinatally-infected youth may have received limited provider and parental preparation to manage their chronic illness independently (Barnes et al., 2013:326). In addition, youth that have more problems, for example, high viral loads, may have received more information from healthcare providers.

In 2006, Grey, Knafl and McCorkle published a framework for the study of self- and family management for chronic conditions (2006:278). Their framework identified risk and protective factors associated with self- and family management. These factors are grouped into health status factors, individual factors, family factors and the environmental context.

Lin, Anderson and Chang (2008:370) developed a self-management model for diabetes which included factors such as self-integration, self-regulation, interaction with health professionals and significant others, self-monitoring and adherence to a recommended regimen which are similar to the self-management skills already described.

HIV is similar to other chronic diseases in that it requires lifetime changes in physical health, psychological functioning, social relations and the adoption of disease specific regimens (Swendeman, Barbara, Ingram & Rotheram-Borusa, 2009:1321). Common self-management tasks and challenges across chronic diseases and HIV is represented in Table 2.1. Several similarities exists between this framework and the frameworks described by Lorig and Holman (2003:2) and Sattoe, et al. (2015:710).

Table 2.1 Self-management tasks and challenges in the physical, psychological and social domains (Swedeman, et al., 2009:1335)

Physical health	Psychological functioning	Social interactions
Framework for understanding illness and wellness Health promoting behaviours Adherence to treatment Self-monitorinig of physical health status Accessing appropriate treatments and services Preventing transmission	Self-efficacy and empowerment Cognitive skills of self-management Reduction of negative emotional states Identity – striving for normalcy	Collaborative relationships with healthcare professionals Self-disclosure of disease status and coping with stigma Positive social and family relationships Social support

The Individual and Family Self-Management Theory (IFSMT) developed by Ryan and Sawin (2009:220), was used to underpin the theoretical framework for this study and is described in chapter 1. It describes the processes of SM slightly differently than other authors. Self-management processes are divided into Self-regulation, Knowledge and beliefs and Social facilitation. This theory describes SM behaviours such as treatment adherence and monitoring symptoms as proximal outcomes of SM processes. Self-regulation processes include: goal-setting; self-monitoring and reflective thinking; decision-making; planning and action; and self-evaluation. Knowledge and beliefs inlcude factual information and perceptions about a health condition including self-efficacy, outcome expectancy and goal congruence. Social facilitation occurs within relationships and is meant to enhance the capacity of the individual to change. It includes social influence, social support and negotiated collaboration. As mentioned in chapter 1, the IFSMT was chosen to underpin the study since it provided a comprehensive and meaningful framework for the identification of variables to test the validity of the developed instrument. Furthermore, a full description of the different SM processes and how these concepts are internally related is provided.

Schulman-Green, Jaser, Martin, Alonzo and Grey, et al. (2012:136) presented another framework for SM processes based on their qualitative meta-synthesis across various chronic conditions. According to these authors, the SM processes described by Ryan and Sawin (2009) does not address the importance of emotional and existential processes such as deriving meaning from the illness experience. This was taken into consideration when developing the items for the adolescent HIV self-management instrument. Schulman-Green et al. (2012:136) grouped SM processes into the following categories: illness needs (disease specific health and health promotion tasks); activating resources (utilising the healthcare

system and obtaining social support) and living with a chronic illness (e.g. coping, reajusting, integrating). They further delineated tasks and skills for each of the processes. These self-management processes are not linear – they are complex and variable according to each individual's experience, life context and immediate priorities. It can also change over time based on an individual's experiences and illness trajectory.

Although common tasks exists between chronic diseases, HIV may differ from other chronic diseases in several ways. These include: adherence to regimens may be complex due to rigid requirements; daily self-monitoring is difficult due to the nature of the disease, for example, no self-administered tests; and social stigma limits social support mechanisms (Human Resources and Services Administration, 2006:1; Swedeman et al., 2009:6). The SM tasks and strategies of adolescents living with HIV in Uganda included taking and adhering to ART, monitoring the condition, maintaining general health, managing disclosure and stigma and adjusting to new roles (Martin, Kiwanuka, Kawuma, Zalwango & Seeley, 2013:697). Currently blood tests, such as VL and CD4 cell count, is required to determine the success of ART and the immune status of the patient and must be performed in a laboratory and requested by a clinician. Patients may experience predictable challenges when it comes to stigma such as shame, discrimination and social rejection. However, this may vary depending on the context (Swedeman et al., 2009:6). Other aspects such as the prevention of transmission and engaging in sexual relationships may also pose a unique challenge. Differences in SM tasks that may particularly be relevant when it comes to adolescents are processes and behaviours specific to the developmental level of the adolescent and the sociocultural context. Adolescents and families have to manage the typical activities and developmental challenges such as going to school and managing peer presssure in addition to HIV.

Paediatric SM involves interactions of health processes and behaviours that patients and families engage in to manage a chronic condition (Modi et al., 2012:477). This definition of SM is neutral, in that efforts to self-manage can affect health outcomes either positively or negatively; condition-focused (applies only to persons with chronic conditions); and treatment-focused (does not focus on the prevention of negative events). These processes and behavours are illustrated in Table 2.2 to show how adding the family dimension to the definition may change the self-management tasks or behaviours through reciprocal processes. Children and adolescents live in complex systems. This model incorporates the Ecological Systems Theory as discussed in chapter 1. There are critical related processes linking SM behaviours and the variables that influence them. These processes are linked to the individual's perception of whether behaviours would be appropriate, the utility thereof and the potential impact on health (Modi et al., 2012:477).

Table 2.2 Self-management processes and behaviours in the individual, family, community and health care system domains (Modi et al., 2012:477)

Domain	Processes	Behaviours
Individual	Determining health care needs Seeking information (disease and treatment related) Communication with health care team	Taking medication Attending clinic appointments Self-monitoring symptoms Lifestyle modifications Behavioural compliance with parental instructions Self care
Family	Determing the adolescents' health care needs Seeking information Allocating treatment responsibility Behavioural management Managing stress, physical and psychological functioning in the family Communitaction with the health care team	Giving medication to the adolescent Attending clinic appointments with the adolescent Monitoring symptoms of the adolescent Supporting lifestyle modifications Parental support and supervision of treatments Providing access to recommended therapies (e.g nutrition, excersise, recreation) Sibling and extended family support
Community	Learning about patients' disease and treatments Degree of social acceptability of the disease Provision of support for treatment Collective beliefs School reintegration	Provision of support for treatment regimens Engagement in patients' disease related activities (e.g. camps) Use of social networks Community support
Health system	Modification of communication styles Shared decision making	Patient advocacy Legistlation and health care reform Healthcare provider training in sociocultural factors

The processes and behaviours unpacked here based on the level or system illustrates that there may be reciprocal engagement in SM tasks required for adolescents. This may be particularly relevant for the adolescent and their immediate family. What is however lacking in the processes and behavours described by Modi et al. (2012:477), is the emotional and social components of care, since the focus is mainly on the medical management of care.

Cox, Fritz, Hansen, Brown and Rajamanickam, et al. (2014:126) identified barriers to self-management amongst adolescents living with diabetes. These are classified under six

domains. The first domain is “understanding and organising”, which relates to understanding and keeping to treatment schedules. The second is “regimen pain and bother” and relate to managing negative effects of treatment and integrating treatment into routines; “denial of disease and consequences”, for example, questioning why they have the illness, not realising the consequences of not taking treatment and prioritising other things above taking treatment is the third domain. The “healthcare team”, which includes the relationship and communication with the healthcare providers and feelings such as trust and respect is the fourth domain and “family”, the relationship and support from their caregiver and family, the fifth domain. The sixth domain is “peer interactions”, which include communication with friends and peer support related to the illness.

Most of the SM frameworks discussed here were developed based on research and literature in developed countries and these SM frameworks may not be suitable for conceptualising SM for HIV in developing countries, especially in sub-Saharan Africa (Martin et al., 2013:298). In Table 2.3 an attempt is made to compare some of the key SM frameworks described in this section.

Table 2.3 Comparison of selected self-management frameworks

Framework	Corbin & Strauss 1988; Sattoe et al., 2015	Lorig & Holman, 2003	Ryan & Sawin, 2009; 2014	Schilling et al., 2009	Modi et al., 2012	Schulman-Green et al., 2012
SM processes described	Medical management Behavioural management Emotional management	Medical management Behavioural management Emotional management	Enhancing knowledge and beliefs (self-efficacy, outcome expectancy, goal congruence) Regulation of skills and abilities (goal-setting, self-monitoring, reflective thinking, decision making, planning, action, self-evaluation, emotional control) Social facilitation (influence, support, collaboration)	Collaboration with parents – frequency of parental involvement	Determining health care needs Seeking disease and treatment related information. Communication with the medical team *(Applied on individual, family, community and health care system level)*	Illness needs (learning, taking ownership of health needs, performing health promotion activities) Activating resources (health care, psychological, spiritual, social, community) Living with a chronic illness (processing emotions, adjusting, integrating illness into daily life, meaning making)
SM skills described		Problem solving Decision making Utilising resources Partnering with healthcare providers Taking action and improving self-efficacy		Problem solving - adjusting regimen themselves and knowing blood values Goals – endorsing potential goals		Acquiring information; monitoring and managing symptoms; taking action to prevent complications, goal setting; decision-making; problem-solving; planning; evaluating, etc. Communicating effectively; making decisions collaboratively; seeking support of family and friends; etc. Dealing with shock and blame; making sense of illness; dealing with stigma; creating a sense of purpose etc.

Framework	Corbin & Strauss 1988; Sattoe et al., 2015	Lorig & Holman, 2003	Ryan & Sawin, 2009; 2014	Schilling et al., 2009	Modi et al., 2012	Schulman-Green et al., 2012
SM behaviours/ activities described			Engaging in treatment / treatment adherence Symptom monitoring	Performing key care activities Communicating with parents, healthcare workers, friends	Taking medication Attending appointments Self-monitoring symptoms Lifestyle modifications Behavioural compliance with parental instructions Self care	

2.7 SELF-MANAGEMENT TASKS IN THE ADOLESCENT DEVELOPOMENTAL STAGE AND THE EFFECT OF HIV ON DEVELOPMENT

Central issues in adolescent development include the development of identity, the importance of adolescents' obtaining some psychological autonomy while still retaining connection to their social context and the role of peers (Lerner & Steinberg, 2009:258).

Keough (2009:2) states that although adolescents may be cognitively mature enough to self-manage, many still tend to remain focused on the present and therefore expecting perfect SM behaviours from them is not realistic. In addition, socialisation and the desire to fit in with their peers and be normal may take higher priority than self-managing their illness.

An individual's brain continues to develop through the adolescent years and the area of greatest change after puberty is the prefrontal cortext which is concerned with executive functions such as monitoring, organising and planning (Lerner & Steinberg, 2009:153). Adolescents' cognitive development is at the formal operational stage. In early adolescence, throughts may still be concrete (in the here and now) and adolescents may not understand that their present actions have future consequences (WHO, 2010:14). During middle and late adolescence thoughts become more adaptable and flexabile. Adolescents can then deal with more complex problems and think abstractly (Piaget, 1970 in Newman & Newman, 2012:354). Key features of formal operations are hypothesising a logical sequence of events and the ability to forsee consequences of actions (Newman & Newman, 2012: 355). For example, in thinking about going away for the holidays, adolescents may consider how long they will be away, what it will cost to travel, with whom they will reside and whether they will be able to access a clinic during the time. They may be able to plan for different scenario's, for example, taking enough medication with them to last the duration of the holiday or asking for a referral letter in order to access treatment at another clinic. An adolescent may also be able to contemplate the various scenario's in which they can disclose their HIV status and possible reactions of individuals to their disclosure.

One needs to keep in mind the enourmous individual variability in cognitive functioning amongst adolescents (Lerner & Steinberg, 2009:152). Both environmental diversity and the the activities adolescents choose to engage in contribute to this variability. For example, participating in a variety of roles or activities facilitates relatavistic thinking through which the adolescent learns that what is acceptable and valued in one situation may not be in another (Newman & Newman, 2012:356).

Although adolescents may lack inductive and argumentive reasoning skills and frequently only consider one dimension or aspect when making decisions, they increasingly develop the potential to manage and use cognitive resources in a purposeful way (Lerner & Steinberg,

2009:180). Early adolescence is increasingly being acknowledged as a critical period where patterns are established that will be resistant to change later on (Lerner & Steinberg, 2009:181). Cognitive skills development may therefore be critical to foster healthy behaviour before risk behaviours start (WHO, 2010:17).

According to the psychosocial stages of Erikson (1986 in Steinberg & Morris, 2001:91), adolescents are at the identity versus role confusion stage. This can include the formation of a personal identity, occupational identity and sexual identity. They may be pre-occupied with physical apprearance and view themselves through their peers and society. Role confusion occurs when they are not able to resolve conflict between self and society. Adolescents' self-concepts become more differentiated and organised as they grow older and they can evaluate themselves globally and along distinct dimensions such as appearance, social relationships, academic performance and morals (Steinberg & Morris, 2001:91). Identity formation occurs when they can be loyal to other people and values. Identification with one's own ethnicity and culture has been associated with higher self-esteem and self-efficacy among minority Black adolescents (Steinberg & Morris, 2009:92). Living with a chronic condition such as HIV which is still highly stigmatised in society may significantly affect the development of a healthy self-concept and identity. Affilitation with a peer group with a similar diagnosis and circumstances may therefore be an imporatant source of support (WHO, 2010:20).

Adolescents become more aware of their emotions and can express a wider range of them (Newman & Newman, 2012:359). They may experience stress and anxiety at this stage, which can be exacerbated by for example, learning about their HIV-positive status, bereavement and loss due to the death of family members or fear of stigma, lack of family support, peer pressure, changes in their physical appearance and conflict with siblings or caregivers (Lowenthal et al., 2014:9). This may result in emotional instability, behavioural problems and non-adherence to HIV treatment. In a Malawian study, significant predictors for depression amongs HIV-positive adolescents included being older, fewer years of schooling and being bullied for taking medication (11.6% of participants reported being bullied for taking medication). Being female, a death in the family, having a girlfriend/boyfriend, failing a school subject/grade, non-disclosure, and dissatisfaction with appearance were associated with higher depression levels (Kim, Mazenga, Yu, Devandra, Nguyen et al., 2015:264).

During adolescence, an understanding of morality is formed which enables adolescents to start aligning their behaviour with their values and beliefs. Kohlberg (1987 in Newman & Newman, 2012:402) holds that adolescents' (aged 10 to 18) moral development is at the conventional stage (stage II). This means that they are concerned with maintaining the existing or conventional rule structure, norms and expectations. Most adolescents would therefore be concerned with obeying rules such as keeping clinic appointments and taking

treatment. Appearing 'good' to others may be what guides their moral choices and behaviour and they may therefore be reluctunt to admit that they have not adhered to treatment. They may also recognise the authority of healthcare workers and may not want to challenge them or ask questions regarding their treatment. As adolescents become aware of intentions of actions, they may judge their own actions based on their good intentions rather than what effect it may have on the other person. For example, they may feel not disclosing their HIV status to a sexual partner is acceptable, especially if they feel there is a low risk of HIV transmission such as using condoms or having an undetectable VL. Over half of perinatally infected HIV-positive adolescents in a United States study reported not disclosing to partners when using condoms (Weintraub et al., 2017:129). Self-disclosure is very challenging for adolescents due to the fear of rejection, stigma, loss of control over private information and a lack of confidence/emotional resources to manage negative reactions. They often report lacking the skills to decide to whom, at what time, how and where to disclose (Thoth, Tucker, Leahy & Stewart, 2014:282).

In younger adolescence, values and beliefs are largely guided by parents, family, culture and religion. As adolescents mature, peers have a greater influence on their values and beliefs and their ability to think abstractly leads them to question and interrogate rules and authority rather than to blindly obey. Moral reasoning may be influenced by traumatic or challenging life experiences such as being abused or exposed to violence or by observing the immoral actions of others. Exposure to various relatonships, information, moral dilemmas and ways of thinking stimulates moral reasoning (Newman & Newman, 2012:403).

Although adolescents gradually begin to take responsibility for their own care, parental support is still needed for younger adolescents. Keough (2009:21) states that the transfer of responsibility for SM usually occurs in late adolescence. In pre-adolescence the responsibility is parent-dominant and becomes transitional in early adolescence. In middle adolescence, SM may be adolescent-dominant for some and transitional for others; while it is adolescent-dominant in late adolescence. Keough, Sullivan-Bolyai, Crawford, Schilling and Dixon (2011:486) examined differences in SM behaviours of adolescents diagnosed with Type 1 diabetes in early, middle and late adolescence. They found that collaboration with parents declined from early, middle to late adolescence and problem solving increased.

The Cincinnati Children's Hospital (2007:24) developed an evidence-based practice guideline for children with chronic diseases. They identified SM tasks based on the developmental stage of the child. For the age group 13 to 18, these tasks include taking treatment when reminded; and eventually taking the treatment on their own. Gradual withdrawal of parental support is advocated and it is an individual process. However, continued parental support may be associated with improved outcomes. Adolescents should be prepared to make judgements

for taking treatment when away from home and recognise and report symptoms. Older adolescents may be encouraged to keep a record of their symptoms and medications. Healthcare workers and caregivers can support adolescents through directly engaging with the adolescent regarding their treatment plans and asking them to identify obstacles upfront and plan to address these. Contracts and reward systems can also be put in place. Other support includes keeping regimens simple and anticipating bothersome side-effects.

A systematic review on developmental challenges in HIV-infected children by Sherr, Croome, Castaneda, Bradshaw and Romero (2014:74) found most studies report some form of cognitive delay for HIV-positive children compared to controls, but that not all domains are necessarity affected. One study found that executive functioning and processing speed were specifically challenging for HIV-positive children. Behavioural problems were noted in some studies, but not in all. The environment, parenting and stimulation may play a very important role when it comes to development, since cognitive performance may be affected by multiple variables. Children living with HIV may be exposed to more challenging environments and social situations that do not facilitate cognitive development. Currently there is mixed evidence of whether being on ART improves developmental outcomes (Sherr et al., 2014:74). One can therefore assume that adolescents with HIV, especially those who were infected perinatally or at a young age, may have some cognitive delay that affects their ability to self-manage.

2.8 THE ILLNESS TRAJECTORY OF ADOLESCENTS LIVING WITH HIV AND ADOLESCENT HIV CARE COMPONENTS

According to the work of Corbin and Strauss (1988) on chronic disease management, each person has an illness trajectory. An illness trajectory is the course of illness. For most people, this starts when they are diagnosed with a chronic disease and ends with death. It represents the impact (through physical symptoms and socially) the condition has on the individual and family (Grey et al., 2006:280).

Adolescents may be diagnosed with HIV during adolescence if they are presenting late or are behaviourally-infected. Perinatally-infected adolescents are diagnosed as infants or children and are only fully disclosed to at a later stage (most often early adolescence). Mavhu, Berwick, Chirawu, Makamba and Copas et al. (2013:5) found that becoming aware of their HIV status is one of the most difficult life events young people living with HIV experience. It is coupled with feelings of despair, hopelessness and expectations of death. Becoming aware of an HIV diagnosis may be followed by a period of denial, especially if the adolescent does not experience any symptoms (WHO, 2010:33). Denial may, however, lead to negative SM behaviours. Adolescents require a lot of support to cope with an HIV diagnosis amongst other normal adolescent challenges.

The illness course of perinatally- and behaviourally-infected adolescents may differ. Without treatment a perinatally-infected adolescent's illness may quickly progress to AIDS and before the advent of ART, most perinatally-infected children did not survive into adolesence (WHO, 2010:30). Some of these adolescents, called "slow progressors" do, however, survive into adolescence without ART. Perinatally-infected adolescents are more likely to suffer from the chronic effects of HIV infection such as delayed growth and development, tend to be younger than behaviourally-infected adolescents and are less likely to be sexually active. ART may have been started at a young age, leading to various changes in ART dosages or regimens by the time they reach adolesence. Paediatric regimens are more complicated with a higher pill burden and more frequent doses (MacDonell, Naar-King, Huszti & Belzer, 2013:92). Concerning support, perinatally-infected adolescents may be living with parents or they may be orphans living with family members or other caregivers (WHO, 2010:30). Although the therapeutic needs of perinatally- and behaviourally-infected adolescents may differ, shared difficulties include medication non-adherence, risky sexual behaviour, psychosocial stressors and comorbid psychiatric illness (Ross, Camacho-Gonzalez, Henderson, Abanyie & Chakraborty, 2010:63).

Behaviourally-infected adolescents likely aquired HIV through risk behaviours (Ross et al., 2010:63). They are older (usually above 15) with normal development and likely to be in a sexual relationship. Generally, they appear well since HIV-infection may remain asymptomatic longer in adolescents compared to adults (WHO, 2010:63). ART regimens may be less complicated since they are likely to qualify for daily fixed-dose combination drugs. Adolescents who acquire HIV during adolescence may have less support due to non-disclosure of their status to family and friends (WHO, 2010:30; MacDonell et al., 2013:86).

If they take their treatment correctly, most adolescents can live a long and healthy life with HIV, with an uneventful illness trajectory. As with other chronic conditions, normal adolescent development may affect the course of the disease. Some adolescents may default their medication during this stage and can suffer severe illness or an early death due to the consequences of high VLs, opportunistic infections and virological resistance. Second or third line ART regimens are more complicated with a higher pill burden. This may lead to a crisis or acute phase where active intervention and support is needed. Other adolescents may be affected by comorbid illnesses such as malignancy, chronic diseases and mental health problems that may alter their illness trajectory. HIV may influence normal development, including psychological development and socialisation (Lowenthal et al., 2014:4). An adolescent's illness trajectory and events changing this trajectory has a direct impact on SM.

Perintally-infected adolescents are likely to have attended paediatric services for years. After a certain age, they may have to transistion to adult care, which may be a difficult period for

them (WHO, 2010:65). Adolescents infected during adolescence may be in paediatric services for a short period before transisioning to adult care or they may start ART in adult care. Both groups may not feel comfortable at either paediatric or adult services and adolescent-specific services are not widely available and accessible (WHO, 2010:65).

A comprehensive care package for HIV-positive adolescents includes prevention and management of chronic complications, regular assessment of psychosocial status, adherence support, age-appropriate sexual and reproductive health services, support with disclosure and transition to adult care (Lowenthal et al., 2014:24,25). Routine HIV care for adolescents should provide information about HIV transmission and sexually transmitted infections, focus on substance and alcohol use and the practice of risky sexual behaviours (Mhalu et al., 2013:6). Transition plans for adolescents should be mindful of the risk of cardiovascular diseases and assessment of bone health, neorocognitive disorders and psychiatric illness (Lee & Hazra, 2015:1).

Adolescent-friendly health services are focused on the comprehensive needs of adolescents. Confidentiality and privacy are very important to adolescents, as is accessibility and short waiting times. Healthcare workers need to be motivated and competent to work with the youth of which key aspects are respect, patience and being non-judgemental (WHO, 2010:34). Characteristics of youth-friendly clinics include changes in the physical environment (dedicated space, décor, entertainment/interactive spaces, internet access and educational materials), social environment (training of staff focused on adolescent development, gender and sexual orientation) and policies such as extended and flexible consultation hours (Tanner, Philbin, Duval, Ellen, Kapogiannis & Fortenberry, 2014:199).

2.9 ADOLESCENTS' PREFERENCES AND COMPETENCIES FOR PARTICIPATION IN HEALTH CARE

Van Staa (2012:137) conducted a study in the Netherlands on a group of adolescents living with various chronic conditions between the ages of 12 and 19. The purpose was to determine their preferences and competencies for hospital consultations.

Adolescents have a strong preference for healthcare providers who are competent, honest and communicate well. They wish to have a say in matters that concern them and want to be taken seriously. Older adolescents want to be treated like adults and want the focus to be on them and not on their parents. For younger ones, the support of their parents is still important. Although adolescents desire to be involved in their own care, their actual participation during hospital consultations was low. There was a gap in what the adolescents perceived their capability for communication to be and their actual behaviour, which may be partly due to the fact that they are not always included in triadic communication (Van Staa, 2012:276).

Interestingly, this study found that it was only in the HIV department that it was standard practice that adolescents were seen alone (Van Staa, 2012:144).

The study also identified four profiles for healthcare delivery and SM using Q-methodology (Van Staa, 2012:277). Four out of five adolescents (79.4%) could be classified in at least one of the four profiles while 20.6% did not fit into any of the profiles. Some adolescents (4.2%) fitted into more than two profiles. Adolescent preferences and competencies for care were classified as follow:

- *Conscious and compliant:* Adolescents who show a high level of involvement in their care, feel more independent and display a higher degree of self-efficacy. They prefer to adhere to treatment to avoid further health problems. However, they also like to pretend that there is nothing wrong with them. This profile fitted 56% of adolescents well, appealing to older, higher educated youth who experience better health. Example: *'As long as I just follow doctor's orders, I don't have to worry.'*

- *Self-confident and autonomous*: These adolescents feel very capable of self-management and can participate in consultations without their parents. They are frank about their illness. However, these adolescents may consciously decide to be non-adherent since they feel that enjoying life is more important than adhering to treatment. Twenty-six percent of adolescents fit this profile well, but there were no demographic variables significantly associated with it. Example: '*I take my own decisions, I will not have my illness limit me.'*

- *Backseat patient*: Feels less capable of self-management and leans on parents because they feel uninvolved and incompetent. It is easier for them to leave the responsibility to their parents and they rely on parents to remind them to take the treatment. They do not want to know about their illness and will not make an effort to ask questions. At least 16% of patients fit this profile well and is associated with being younger, physically disabled and lower educated. Example: *'If my parents know what to do, it's ok.'*

- *Worried and insecure*: Lacks confidence because they worry about their own health prospects and need parental support. This profile fits 25% well, mostly younger and lower educated girls who also experience poor health and a low quality of life. Example: *'Just imagine that things will go wrong later.'*

Generally all the profiles, except the "worried and insecure" adolescents want to be consulted regarding transfer to adult care and only the "backseat patients" did not look forward to adult transfer. Peer contact was only desirable for "self-confident and autonomous" adolescents. These profiles may be used to identify risky behaviours such as a lack of independence,

depression and non-adherence. Van Staa (2012:280) further mentions that the profiles may represent a stable self-management typology, a character trait or a temporary state in that some adolescents may further develop more self-management skills.

2.10 PROTECTIVE AND RISK FACTORS INFLUENCING SELF-MANAGEMENT IN ADOLESCENTS WITH HIV: APPLICATION OF THE ECOLOGICAL SYSTEMS THEORY

Several factors may influence chronic disease SM in adolescents living with HIV. These factors include individual, sociocultural (family and community) and health system domains and can be classified as either modifiable or non-modifiable (Modi et al., 2012:477). Ecological models such as the Ecological Systems Theory and the Bioecological Model of Bronfenbrenner identifies various environmental systems in which a person interacts and focuses on the components of process, person, context and time as central to human development (Rosa & Tudge, 2013:251).

The Self- and Family Management of Chronic Conditions Framework developed by Grey and colleagues (Grey et al., 2006:278) also identifies risk and protective factors that affect SM. They classified these factors into i) health status (severity of condition, health status, trajectory, genetics); ii) individual factors (age, gender, psychosocial characteristics, diversity/culture); iii) family factors (socioeconomic status (SES), structure, function); iv) environmental context (social networks, community, health care system). Each of the factors are also linked with outcomes, for example, health status outcomes such as disease control and individual outcomes such as adherence and quality of life. These factors are similar to the factors in the Bioecological Model.

2.10.1 Individual or person

Individual influences of self-management include age, gender, ethnicity and cognitive functioning, for example, intelligence quotient (Modi et al., 2012:477).

Female adolescents in South Africa were found to be at a higher risk for HIV/AIDS mortality than males (De Wet et al., 2014:13). According to Grey et al. (2006:280) women may neglect SM. However, it is not clear if that would apply to adolescents or all ethnicities. Culture affects how health is defined as well as how individuals communicate. This, in turn, may influence SM behaviours.

Concerning ethnicity, Black South Africans have the highest HIV prevalence, followed by Coloureds (Shisana et al., 2014:25). Ethnicity, culture, educational level, language and sexual orientation may affect an individual's approach to self-management (Grey et al., 2006:280).

Schulman-Green et al. (2012:140) reports that socio-economic status and culture can affecct SM. It is therefore important to understand how SM is conceptualised and carried out in different social contexts. Younger age may also be associated with higher individual and family SM needs, although this may change over time (Grey et al., 2006:280).

Some individual influences may be modifiable such as psychological and behavioural problems. Perinatally-infected adolescents are particularly prone to depression and attention-deficit hyperactivity disorder (ADHD) due to the effect of HIV on their neurological development, which may be associated with poor behavioural outcomes (Mellins & Marlee, 2013:1). Sharp, Venta, Marais, Skinner, Lenka and Serekoane (2014:1174) conducted a study on AIDS orphans between the ages of 7 and 11 in the Free State province of South Africa and found that 15% of children met full criteria for psychiatric disorders and almost half met criteria for intermediate levels of psychopathology. Most of the participants screened positive for ADHD, followed by anxiety, disruptive behaviours and affective disorders. HIV-positive adolescents in Zimbabwe had poor psychosocial well-being, with 63% at risk of depression (Mavhu et al., 2013:1). Depression and avoidance coping decreases SM capability, whereas self-efficacy and integration enhances SM capability (Grey et al., 2006:280).

Self-efficacy and adaptive health beliefs are associated with better SM (Modi et al., 2012:478). According to Sawin et al. (2009:27), the development of specialised knowledge, skills and self-efficacy creates a positive feedback loop whereby adolescents improve their SM. Barnes et al. (2013:323) identified the following predictors for better HIV knowledge among American HIV-infected youth aged 13-21: being behaviourally versus perinatally infected and providing communication related to CD4 count and VL. In Tanzania, being on ART and not knowing the serostatus of one's partner predicted the practice of multiple sexual partnerships (Mhalu et al., 2013:1).

A qualitative study that included 111 adolescents, 21 parents and 38 healthcare providers in Zambia explored the experiences of adolescents living with HIV. It was found that resilience (increasingly becoming more capable of withstanding difficulties associated with having HIV) and internalised stigma shape the experiences of adolescents after being diagnosed with HIV, their outlook on life (future aspirations) and being connected through relationships (Mburu et al., 2014:9). Many adolescents had a sense of purpose, were motivated and carried out a range of duties such as looking after siblings or their own children. However, in some instances adolescents had internalised stigma, accompanied by low self-esteem and self-pity, that affected their ability to engage with their family and peers (Mburu et al., 2014:14).

Disclosure is important since adolescents can only be involved in their own treatment and actively seek support if they are aware of their status and why they need to take treatment. The active participation in decisions regarding their treatment also improves their self-confidence and sense of control over their lives (Skovdal & Daniel, 2012:19).

Clinical factors such as the health status of the adolescent, comorbidities, the illness trajectory and the complexity of the treatment regimen may also influence SM (Schulman-Green et al., 2012:140). Higer disease severity and regimen complexity increases SM needs (Grey et al., 2006:281).

2.10.2 Family context

Although adolescence is a period of gradual separation from parents, the family may still be an important source of support. It is important to understand self-management in the family and community context in which it takes place (Grey et al., 2006:282). Family structure, socioeconomic status (SES) and ethnic background are considered factors that are not easily modified, while caregiver involvement and family functioning are considered modifiable factors of SM. In South Africa, poor socioeconomic circumstances with a lack of basic necessities such as formal housing, sanitation and water, have been associated with higher HIV prevalence rates (Shisana et al., 2014:25). Lower SES is also associated with poorer SM (Grey et al., 2006:280).

Poor parental or caregiver health, disability and mental health as well as child abuse and poverty have been associated with poorer outcomes for children, while parent-child involvement and communication have been associated with better functioning (Mellins & Marlee, 2013:1; Cluver et al., 2013:191). Grandparents are often the primary caregivers of adolescents. Elderly caregivers may not have the financial support to care for adolescents and may suffer from stress and depression, particularly if they also lack social support (Skovdal & Daniel, 2012:155). Orphanhood is common amongst adolescents living with HIV in Zimbabwe, with the majority (76%) in one study reporting that their mother (21%), father (38%) or both (40%) had died. Many of the adolescents had changed households and when they resided with other families, perceived that they were treated diffently from the other children in the household (Mavhu et al., 2013:4). South Africa has the highest number of children (2.5 million) globally who have lost one or both parents due to AIDS. These children are more vulnerable to poverty, disease and violence (UNICEF, 2013b:24). Illness and death due to HIV may give rise to households with non-traditional arragements and inadequate support structures, resulting in the necessity for adolescents to find support from outside their immediate family (Skovdal & Daniel, 2012:160). Better family functioning is associated with better SM since it usually relates to better support, adequate resources, fewer stressors and

the ability to find positive meaning. Family closeness, supportive relationships, caregiver coping skills, direct communication about the illness and good organisation were linked with better family- and individual outcomes (Grey et al., 2006:280).

Instability in parent-child coresidence, including separation, death, migration, fostering and reunification influences adolescent development. A study in Cape Town, South Africa found that both maternal and paternal instability in coresidence was associated with earlier sexual initiation amongst Coloured and Black girls and a higher school drop-out rate/poor progress amongst Coloured girls and boys (Marteleto, Cavanagh, Prickett & Clark, 2016:33). In Tanzania, family support was associated with sexual abstinence following an HIV diagnosis and fewer sexual partnerships (Mhalu et al., 2013:5).

There may be a significant association between parental substance abuse and child adherence to ART (Naar-King, Arfken, Frey, Harris, Second & Ellis, 2007:626). Low household income and low caregiver intelligence quotient was also found to be associated with high VLs in children (Usitalo et al. 2012:112). However, Müller, Bode, Myer, Stahl and von Steinbüchel (2010:129) found that family socioeconomic factors were not associated with adherence or viral suppression in South African children.

Parental involvement can either hinder or facilitate adolescents' development of self-management (Sattoe et al., 2015:711). Although family members may become over-protective, Mburu et al. (2014:14) report that family members played a major supportive role in reminding adolescents to take their treatment, encouraging them if they are experiencing side-effects and making them feel valued. Young adolescents especially benefitted from the support of caregivers. This study also found that poor or delayed disclosure created emotional difficulties for adolescents. Disclosure is often delayed due to the fact that sexuality is considered a sensitive topic in many cultures and parents do not often talk to their children about it.

Although familiy and peers may support adolescents in taking their treatment, they may also disclose their HIV status inappropriately (third party disclosure) (Mburu et al., 2014:9). This can make adolescents feel that they have limited control over to whom, when and how to disclose and causes fear of discriminaton and rejection from their peers should they disclose their HIV status.

2.10.3 Community context

Individuals and families manage chronic conditions in the context of the broader community that include the school, peers and neighbourhood. School influences such as curriculum content, policies and support structures influence SM on a systemic level. Illness-related

stigma, peer support and social networking are additional community factors that influence SM (Modi et al., 2012:477). Community violence and HIV/AIDS related stigma are important mediating factors that negatively impact on child outcomes in South Africa (Cluver et al., 2013:190). Disclosure of the child's and caregiver's HIV status, reduced HIV stigma, the caregiver's attitude towards the healthcare system and the ability of the healthcare provider to communicate in the caregiver's primary language was associated with higher viral suppression rates in children (Müller et al., 2010:129). Stigma and discrimination (actual and fear of potential discrimination) in schools were found to negatively influence adolescents' experiences and their quality of life (Mburu et al., 2014:9). In contrast, communty-based interventions, youth clubs and youth corners in HIV centres provided an environment/"transformative social spaces" where adolescents could speak to peers and healthcare providers in order to develop a better understanding of their own needs and challenges. In a study conducted amongst HIV-positive adolescents in Zimbabwe, Mavhu et al. (2013:1) found that although support group attendance was helpful, life outside the group was very challenging due to verbal abuse, stigma and discrimination.

Peers who are living with HIV were found to be a very important source of psychological support and friendship for adolescents (Mburu et al., 2014:13). This peer support structure also helps adolescents to form their identity and to 'normalise' living with HIV in a community without stigma.

2.10.4 Healthcare system

Healthcare system factors such as the quality of relationships and communication with healthcare providers can affect SM (Schulman-Green et al., 2012:140). A healthcare environment and personnel that are equipped to deal with the needs of adolescents may positively impact SM. This may include adolescent-friendly environments, flexible clinic hours and family- and adolescent-centred communication techniques. Healthcare workload, time and resource constraints and inexperience in adolescent care may negatively impact on the ability of healthcare workers to engage with adolescents and their families (Modi et al., 2012:479; Mburu et al., 2014:9). Adolescents report that stigma in HIV clinics is common and that frequent visits to the clinic impacts on their personal lives and interrupts their daily routines (Mburu et al., 2014:14). It is also important that adolescent-friendly services are decentralised.

Important influences beyond medication adherence exists that impacts on the therapeutic success of children on ART. These include caregiver's attitudes, knowledge and understanding of treatment, as well as the relationship between the child, caregiver and the healthcare professional (Müller et al., 2010:137). This may mean that the broader definition

of self-management, which includes complex processes and relationships, may shed more light on treatment efficacy in children and adolescents.

2.11 SELF-MANAGEMENT AND RESILIENCE

Adolescents living with HIV experience significant threats to their development due to their diagnosis and possibly also due to their social circumstances. According to Mburu et al. (2014:15), resilience is a major factor shaping the experiences of adolescents living with HIV and enabling them to come to terms with their diagnosis, having hope for the future and maintaining meaningful relationships.

Resilience, the phenomenon of "bouncing back" from adversity, or the capacity to adapt, recover from or remain strong in times of hardship is both a process and an outcome of interactions between the individual and their social context (Theron & Theron, 2010:1; Skovdal & Daniel, 2012:153,156). As with self-management, the concept of resilience can also be viewed as a trait, process or outcome. It is best viewed on a continuim that could be present in varying degrees in different aspects of life and changes as a person develops (Southwick, Bonanno, Masten, Panter-Brick & Yehuda, 2014:2). The psychological application of resilience refers to meeting developmental goals in spite of adversity or sustained competency under stress. Ecologically, this is often defined as the ability to return to a reference state or to withstand a disturbance (Thorén & Persson, 2015: 68,69).

Research on resilience aims to understand resilience processes that account for good outcomes despite serious threats to adjustment or development (Masten, 2001:228). Masten (2001:228) further states that these developmental threats or risks can be inverted to create resources, for example, replacing poor parenting with good parenting. If enough resources are therefore added or if risk-asset levels are altered, it may counterbalance negative effects of high adversity and maintain outcomes at normative levels.

According to Theron and Theron (2010:8), resilience depends upon certain individual, family, community and cultural protective resources. Individual factors that encourage resilience in a South African context are personality traits (optimism, autonomy, conscientiousness and assertivenes), problem solving skills, positive cognitive appraisal, a sense of self-worth and an internal locus of control.

Protective factors in families include having both parents and the mother's capacity to bond with her child (especially in violent contexts). Youth from Black townships often report that their mothers modeled resilience through being "pillars of strength" (Theron & Theron, 2010:2). Supportive family relations such as joint participation in activities, being loved and valued in the family system, opportunities to pursue education and consistent family rules, were found

to, amongst others, enable adaptation in the context of HIV/AIDS (Theron & Theron, 2010:2). However, even in the case of absent immediate support structures, as in the case with AIDS orphans or child-headed households, children can demonstrate resilience despite these challenges (Skovdal & Daniel, 2013:160).

In the South African context, schools are considered to be a good community resilience resource (Theron & Theron, 2010:2). In general, teaching staff and schools can enable youth resilience by creating a safe and secure space. However, schools do not seem to be a safe space for youth living with HIV due to stigma (Mburu et al., 2014:9). Peer relationships also promote resilience since it fosters social acceptance and promotes positive identity formation. Communities encourage resilience if they provide youth with opportunities to participate in activities that promote self-efficacy, provide access to recreational activities, foster a sense of security and cultivate belonging (Theron & Theron, 2010:3). Cultural or religious practices can also encourage resilience, but cultural practices that encourage resilience in the South African context remains largely unexplored (Theron & Theron, 2010:3).

According to Skovdal and Daniel (2012:160), the extent to which children affected by HIV can demonstrate resilience is dependent on several factors, namely, the quality of the social environment (including resources); children's individual skill and their ability to harness support; and community participation and meaningful interaction.

The same factors that influence resilience may therefore impact self-management. Family, peers and the community can create an environment that can either affirm or negate adolescent HIV self-management. There may be a reciprocal relationship between adolescents' resilience and their connectedness to family, peers and their community. Liebenberg, Ungar and Van de Vijver (2012) developed the Child and Youth Resilience Measure (CYRM) to measure the individual, relational, communal and cultural resources that may enhance resilience and can be used for screening for resilience processes in the lives of adolescents.

The concepts of self-management and resilience appear to be closely related. However, no studies could be found that specifically explored the relationship between self-management and resilience.

2.12 SELF-MANAGEMENT INTERVENTIONS AND PROGRAMMES

SM interventions enhance the development of SM skills (Ryan & Sawin, 2009:218). It promotes behaviour change, decreases healthcare costs and increases quality of life or well-being. Self-management education transcends traditional knowledge-based patient education and includes processes that develop problem-solving skills and improve confidence or self-

efficacy (Van Staa, 2012:180). Nurses and healthcare workers who work with adolescents must be able to strengthen SM skills in adolescents living with chronic conditions and therefore should be able to identify those adolescents who might be less likely to perform SM tasks.

Lorig and Holman (2003:2) identified in 2003 that most patient education programmes do not deal with all three broad SM tasks (medical-, emotional- and role management) and futher stressed that self-management education programmes should be based on the patient's peceived problems and needs. A systematic review by Sattoe et al. (2015:707) on SM interventions for young people with chronic conditions found that most interventions (46.2%) were aimed only at medical management, with little focus on the social and emotional components of SM. In addition, most interventions were in Western countries with a predominant focus on diabetes and asthma.

There is sufficient evidence to support a positive short-term effect of SM programmes on the physical, psychological, knowledge and behavioural outcomes of adults living with HIV (Millard, Elliott & Girdler, 2013:103). However, a systematic review by Aantjes, Ramerman and Bunders (2014:185) found that the literature is not very relevant for the development of HIV SM strategies in the context of sub-Saharan Africa. Evidence related to SM in sub-Saharan Africa will inform strategies that are tailored to the needs of patients, in particular adolescents living with HIV.

Traditional and SM education differs in that in terms of content, traditional education focuses on the provision of information about the disease whereas SM education focuses on teaching problem-solving skills. With traditional education the assumption is that increased knowledge and compliance with treatment plans will lead to improved outcomes, whereas with SM, improving patients' self-efficacy to manage their chronic condition improves outcomes (Bodenheimer et al., 2002:2469). The key SM skills that education programmes are build around are problem-solving, decision-making, resource utilisation, forming partnerships and taking action. Another aspect of SM education is self-tailoring, which means that the patient identifies the problem and then uses SM skills to design their own action plans.

2.13 ADHERENCE

Adherence and SM are two closely-related concepts. The literature more often refers to adherence interventions and adherence amongst adolescents who live with HIV than the concept of SM. As mentioned previously, adherence and SM is not synonymous. Adherence to treatment in the context of this study is viewed as a SM behaviour that is a proximal outcome of SM processes (Ryan & Sawin, 2014). Poor adherence to treatment could therefore be an indication of poor SM.

Non-adherence to treatment is a common problem in adolescents and in one study more than one third of adolescents reported non-adherence within the last three days (Chandwani, Koenig, Sillc, Abramowitz, Conner & D'Angelo, 2012:245). Mavhu et al. (2013:5) found in their study conducted in Zimbabwe that only 16% of adolescents living with HIV self-reported more than 95% adherence. Reasons for missing medication doses included forgetting, travelling, having to conceal their treatment from others, a lack of travel money to collect medication and poor monitoring from parents. Generally, younger adolescents seem to have better adherence than those 16 years and older and those who had a higher risk of a mental disorder also had poorer adherence, although these were not found to be predictors of adherence (Mavhu et al., 2013:5). In a study in the United States, common barriers to adherence included forgetting, not wanting to be reminded of HIV and not feeling like taking medication or needing a break. Perinatally-infected adolescents reported significantly more barriers than behaviourally-infected adolescents. A greater number of reported barriers were associated with psychological distress amongst perinatally-infected adolescents and substance use amongst behaviourally-infected adolescents. Reporting that they "forgot" may be easier for adolescents than saying that they made a decision not to take the tablets (MacDonell et al., 2013:86).

Several non-adherence predictors in perinatally- and behaviourally-infected adolescents in the United States were identified by Chandwani et al. (2012:242): acquiring HIV behaviourally; severity of illness (having had AIDS); internalising behavioural problems; difficult treatment regime; discussing disease indicators with the provider (possibly due to previous non-adherence); missing doses because of forgetting or being depressed; and the use of drugs. Non-adherence can also sometimes be a conscious decision made by the adolescent that may be triggered by feeling depressed (Mavhu et al., 2013:5). Treatment regimens need to be simple and fit into the busy schedule of adolescents.

2.14 MEASURING SELF-MANAGEMENT

A range of SM and self-management self-efficacy scales have been developed that will be discussed briefly in the sections below.

No SM instrument could be found that has been used in adolescents with HIV and most other SM instruments have only been used in developed countries. Contextual issues need to be taken into consideration when selecting instruments. Specifically, these contextual issues include the characteristics of the population, the health concern, the cultural and historical contexts, the research goals and administration issues. Population characteristics that may have an affect on instrument measurements are age, gender and education level. Instruments need to be adapted to include cultural assumptions and beliefs about health and well-being. Historical or political events may cause changes in the language, knowledge base, societal norms, values and attitudes that may influence how participants interpret questions. In

addition, instruments need to reflect the latest research regarding healthy behaviours or health indicators necessitating the need to constantly evaluate instruments for relevance (Switzer, Wisniewski, Belle, Dew & Schultz, 1999:399).

2.14.1 Adolescent Self-Management and Independence Scale

The Adolescent Self-Management and Independence Scale (AMIS II) was developed in 2004 by Buran, Sawin, Brei and Fastenau. This scale consists of 17 items measuring the constructs of SM and independence such as medication management, ordering supplies, making appointments, preventing complications, advocacy, access, transportation, household and community living skills. It uses a scale from '1' for total assistance needed to '7' for no assistance needed. The instrument was created to be used with adolescents who have a wide variety of chronic health conditions, but it has only been used with adolescents who have spina bifida, and has a reported Cronbach alpha of 0.91 with that population (Sawin et al., 2009:37). Although this scale was developed for different chronic conditions, items such as ordering supplies and making appointments are not applicable within the South African public healthcare context.

2.14.2 Self-Management of Type 1 Diabetes in Adolescence (SMOD-A)

The Self-Management of Type 1 Diabetes in Adolescence (SMOD-A) questionnaire developed by Schilling et al. (2009:228) consists of 52 items in the following sub-scales of SM: collaboration with parents; care activities; problem solving; communication; and goals. These activities and process are measured on a four-point Likert scale based on how often the adolescent engages in the processes or activities (never through always) and are specifically related to diabetes. Cronbach alpha has been reported ranging from 0.71 to 0.85 for the sub-scales. The questionnaire was developed based on qualitative interviews and a concept analysis by the authors identifying activities of SM, processes of SM and goals of SM as categories. This instrument provided a good framework for SM processes, but the items are specific to diabetes self-management.

2.14.3 Perceived Medical Condition Self-Management Scale (PMCSMS)

The Perceived Medical Condition Self-Management Scale (PMCSMS) is a generic instrument developed to assess self-management self-efficacy for various medical conditions. According to Wallston et al. (2010:109), the PMCSMS demonstrated reliability for the use with an HIV population (Cronbach alpha of 0.78). Self-efficacy is considered to be central to the self-regulatory behaviours that constitute self-management of a chronic disease (Wallston et al., 2010:110). The PMCSMS consists of 8 items (of which four are reverse scored) and measures the perceived ability (self-efficacy) of HIV-positive patients to manage their disease.

Responses are measured on a six-point Likert scale from 'strongly disagree' to 'strongly agree'. The elements include: i) problem solving related to disease management; ii) efforts to change; iii) self-handling or disease management; and iv) successful goal attainment. Due to the instrument consisting of only eight broadly phrased items and the focus being on adults, it was not considered adequate to comprehensively measure adolescent HIV self-management. Further, the instrument was developed and adapted in the United States and there is no record of the instrument being used in an African context.

2.14.4 HIV Self-management scale for women living with HIV/AIDS

This scale was developed to measure the SM of women living with HIV in the United States by Webel et al. (2012:72). The scale has 28 items divided into three broad domains: daily self-management health practices; social support and HIV self-management; and the chronic nature of HIV self-management. The domains explained 48% of the variance in the scale and the domain reliability ranged from 0.72 to 0.86. The scale has several items that could be applicable to adolescents, but the focus was on adult women who live with HIV and therefore could not be used without adaptation to the context of adolescents. It has also only been used in the United States.

2.14.5 On Your Own Feet Self-Efficacy Scale (OYOF-SES)

The On Your Own Feet Self-Efficacy Scale (OYOF-SES), was developed by Van Staa (2012:178) for children living with a range of chronic conditions in the Netherlands, as part of a PhD thesis. The instrument measures generic self-efficacy for management of chronic conditions at home, in social life and during hospital consultations. She argued that self-efficacy is the key mediating variable for self-management behaviours. The OYOF-SES is a 17-item questionnaire subdivided into three sections: self-efficacy in coping with the condition; self-efficacy in knowledge of the condition; and self-efficacy in skills for indepentend hospital visits. The items are measured with a Likert scale ranging from 1=No, certainly not; 2=No, probably not; 3=Yes, probably; 4=Yes, certainly. Chronbach's alpha for the instrument was 0.85 and the instrument had predictive validy for health-related quality of life and observed self-management during hospital consultations. Although this scale had several meaningful items that could be used in an instrument to measure adolescent HIV self-managment, the contexual appropriateness of the items have to be assessed. Further, the instrument does not include all the SM process concepts, for example, social facilitation.

2.15 INSTRUMENT DEVELOPMENT AND PSYCHOMETRIC TESTING

Measurement instruments that intend to reveal levels of theoretical variables not readily observable by direct measures are called scales (DeVellis, 2012:11). The underlying

phenomenon or construct that a scale of items measures is called the latent variable and is regarded as the cause of the item score. The Classical Measurement Model/Classical Test Theory asserts that an observed score, results from the summation of a true score plus some degree of error. Each item in the scale measures the latent variable at an equal level (DeVellis, 2012:23).

Foxcroft and Roodt (2009:67) and DeVellis (2012:73) outlines several steps in the development of a psycholocial measure or scale. These steps were followed in the study and are briefly discussed here.

2.15.1 Determining what should be measured

Planning involves specifying the aim of the measure and defining the content thereof (Foxcroft & Roodt, 2009:67). The developer should state the construct that will be measured, whether it will be used for screening or diagnosis, the population group of interest, if it will be individually or group-administered, paper or computer-based and whether it is normative, ipsative or criterion-referenced.

The construct (content domain) should be operationally defined by undertaking a theoretical literature review that can include a concept map. It is important that the concept is comprehensively defined. Measures developed for multicultural and multilingual groups need to be explored in terms of each group's understanding and values of the construct (Foxcroft & Roodt, 2009:68).

The purpose of the measure, for example, whether it needs to discriminate between different groups of people, must be established. This is known as criterion keying and may mean in the context of this study, trying to ascertain which aspects of self-management adolescents who are at risk for non-adherence struggle with, and thus including those aspects (Foxcroft & Roodt, 2009:68).

2.15.2 Generating an item pool

A variety of sources can be used for item writing such as literature, theories, existing measures and qualitative data. Wording must be clear and concise and the vocabulary/reading difficulty level appropriate for the target audience (Foxcroft & Roodt, 2009:70). One central theme should be covered in an item, avoiding ambiguity. Instrument developers usually develop three to four times the number of items that they may use in the final item pool (DeVellis, 2012:80).

The format of the measure is determined including the response format. Response formats can take various forms such as a Likert Scale or a Visual Analog Scale. There should also be a time frame for items (DeVellis, 2012, 93).

The pool of items are administered to a small number of persons from the target population for qualitative review. Based on the feedback, certain items may have to be revised or re-written (Foxcroft & Roodt, 2009:71).

After item development, items should be submitted to a panel of experts for review and evaluation (DeVellis, 2012:100). Experts evaluate whether the items fully tap the construct and the cultural, linguistic, and gender appropriateness (Foxcroft & Roodt, 2009:71). Experts are provided with a working definition of the construct and they rate how relevant each item is to what it intends to measure. They can also comment on item clarity and conciseness and point out aspects that were not included (DeVellis, 2012:100).

2.15.3 Assembling and pre-testing the experimental version of the measure

Items are arranged in a logical way and formatted in a questionnaire with clear administration instructions. Instructions should be pre-tested with a sample from the target population and the fieldworkers that will assist with the administration of the questionnaire should be comprehensively trained (Foxcroft & Roodt, 2009:71).

DeVellis (2012:102) holds that items that pertain to construct validity should be included at this stage rather than mounting a separate validation effort after finalising the scale. These measures are selected based on the theory underlying the construct.

The measure is then administered to a development sample of the target populaiton. The sample should be large, although sources differ regarding an acceptable sample size. DeVellis (2012:102) suggest 300 individuals noting that some scales have been developed with fewer participants. When the ratio of participants to items is low, correlations among items can be influenced by chance to a substantial degree. A sample size of 300 has also been suggested in Pallant (2016:184) or alternatively a participant to item ratio of five to ten participants per item.

During the pretesting of the experimental version of the measure, quantitative information regarding the performance of each item is gathered. Further, qualitative information is collected concerning the administration process. This includes, for example, which items participants generally seemed to find difficult or did not understand (Foxcroft & Roodt, 2009:71).

2.15.4 Item analysis

After administering the initial pool of items to an appropriately large and representative sample, items are evaluated to identify which items are appropriate for inclusion in the final scale. This includes analysis of item performance, factor analysis and coefficient alpha (DeVellis, 2012:104).

The purpose of item analysis is to determine whether each item serves the purpose for which it was designed. Since Classical Test Theory assumes that all the items measure the same undelying latent variable, items that are highly intercorrelated are preferred (DeVellis, 2012:107). Another favourable attribute is relatively high variance. If all participants answer the item identically (zero variance), it will not discriminate between individuals with different levels/measures of the construct. Mean item scores close to the middle of the range of possible scores are the most desirable (DeVellis, 2012:107). Discrimination power is also determined by evaluating item-total scale correlations. A positive item-total scale correlation indicates that the item discriminates between those who do well and those who do poorly in the measure. A correlation of 0.20 is considered the miminum acceptable discrimination value (Foxcroft & Roodt, 2009:72).

One of the most important indicators of the quality of a scale is the reliability coefficient alpha. Once items with a noncentrical mean, poor variability, low item-scale correlations and weak inter-item correlations have been removed, the reliability coefficient can be computed. An alpha below 0.6 is unacceptable and if it is above 0.9, researchers should consider shortening the scale; an alpha of between 0.8 and 0.9 is the most acceptable (DeVellis, 2012:108).

Factor analysis determines the latent variables underlying a set of items by identifying categories of similar statements. It is also used to identify item performance, for example, items that do not fit into a factor category or fit into more than one category can be identified and considered for elimination (DeVellis, 2012:108, 117).

Performance on items may be affected by other variables and researchers may motivate, based on their experience, logic and theory, for inclusion of items in the final measure even if the items demonstrated poor item characteristic statistics (Foxcroft & Roodt, 2009:72).

2.16 CONCLUSION

The concept of SM has been studied by several researchers since the original publication of Corbin and Strauss (1988) that described the “work” that individuals living with a chronic illness and their families engage in on a daily basis to manage their chronic illness and maintain health. Self-management processes take place within an individual, family and the social context. Certain skills such as planning and problem-solving is key to effective SM and these

can be supported by increasing patient self-efficacy. Self-management is influenced by the developmental stage of the individual. Adolescence is a period of rapid physical, emotional and social development which may impact on the ability of the adolescent to self-manage. Adolescents who are living with HIV may be affected by various individual and environmental challenges that compromises their ability to self-manage and consequently, to attain good health outcomes. Various instruments have been developed to measure SM, but none specific to adolescents who live with HIV in a low-resource setting such as South Africa. The development of a measurement scale is a systematic process that ultimately aims to develop a list of items that accurately measures a latent concept which in this case is adolescent HIV SM. The next chapter discusses the methodology used in the study.

CHAPTER 3
RESEARCH METHODOLOGY

3.1 INTRODUCTION

The study was conducted over four phases. First, an overview of the research design is given and then the methods used in each study phase are discussed separately.

3.2 OVERVIEW OF DESIGN

The research design was an exploratory sequential mixed-method design. In this process, the researcher blends an interpretivist stance with an ontology that multiple contradictory, but equally valid accounts of the same phenomenon can exist; with a post-positivist stance of objectivity, by using factor analysis to examine the structure of items that emerge from qualitative analysis as a means of furthering construct validation (Onwuegbuzie et al., 2010:58). These types of analyses involve abductive logic (movement between inductive and deductive logic) and intersubjectivity (agreement that reality is socially constructed). It requires a balance between emic perspectives of the participants in the development of the instrument and etic perspectives stemming from theories and the researcher's a priori assumptions. Instrument fidelity includes several steps taken by the researcher to develop an instrument that has optimal appropriateness and utility. These steps are described in the four phases of the study depicted in Table 3.1. The research process followed in each of the phases will be discussed separately.

Table 3.1 Phases and methods for the study

Phase	Objective	Sample	Method	Presentation in dissertation
1	Explore the realisation of adolescent HIV self-management from the perspectives of adolescents, caregivers and healthcare workers.	6 adolescent individual interviews 5 adolescent focus groups (36 participants) 6 caregiver individual interviews 6 healthcare worker individual interviews	Qualitative - Interpretive Phenomenology	Findings in chapter 4.
2	Identify items for the instrument.	Triangulation of data from phase 1, theoretical framework, existing instruments and literature		Discussion in chapter 5.
3	Design the instrument.	Workshop One adolescent group 13-15 years (2 participants); one adolescent group 16-18 years (5 participants);one caregiver group (4 participants) Delphi survey (expert review – 11 participants)	Qualitative – Focus groups and consensus methods	Findings and discussion in chapter 6.

Phase	Objective	Sample	Method	Presentation in research report
3	Pilot test the instrument.	33 adolescents	Quantitative – cross sectional survey with cognitive interviewing	Findings and discussion in chapter 6.
4	Perform item analysis and determine instrument validity and reliability.	385 adolescents, sampled from 11 ART sites	Quantitative – cross sectional survey	Findings and discussion in chapter 7.

Evaluation of the developed instrument as well as the development process was done as part of the final phase of instrument development (Onwuegbuzie et al., 2010:67). This reflection is discussed in chapter 8.

Through each of the phases, the Adolescent HIV self-management (AdHIVSM) instrument was developed, refined and tested. The development of the scale, including the sample used and items in each phase is illustrated in Figure 3.1.

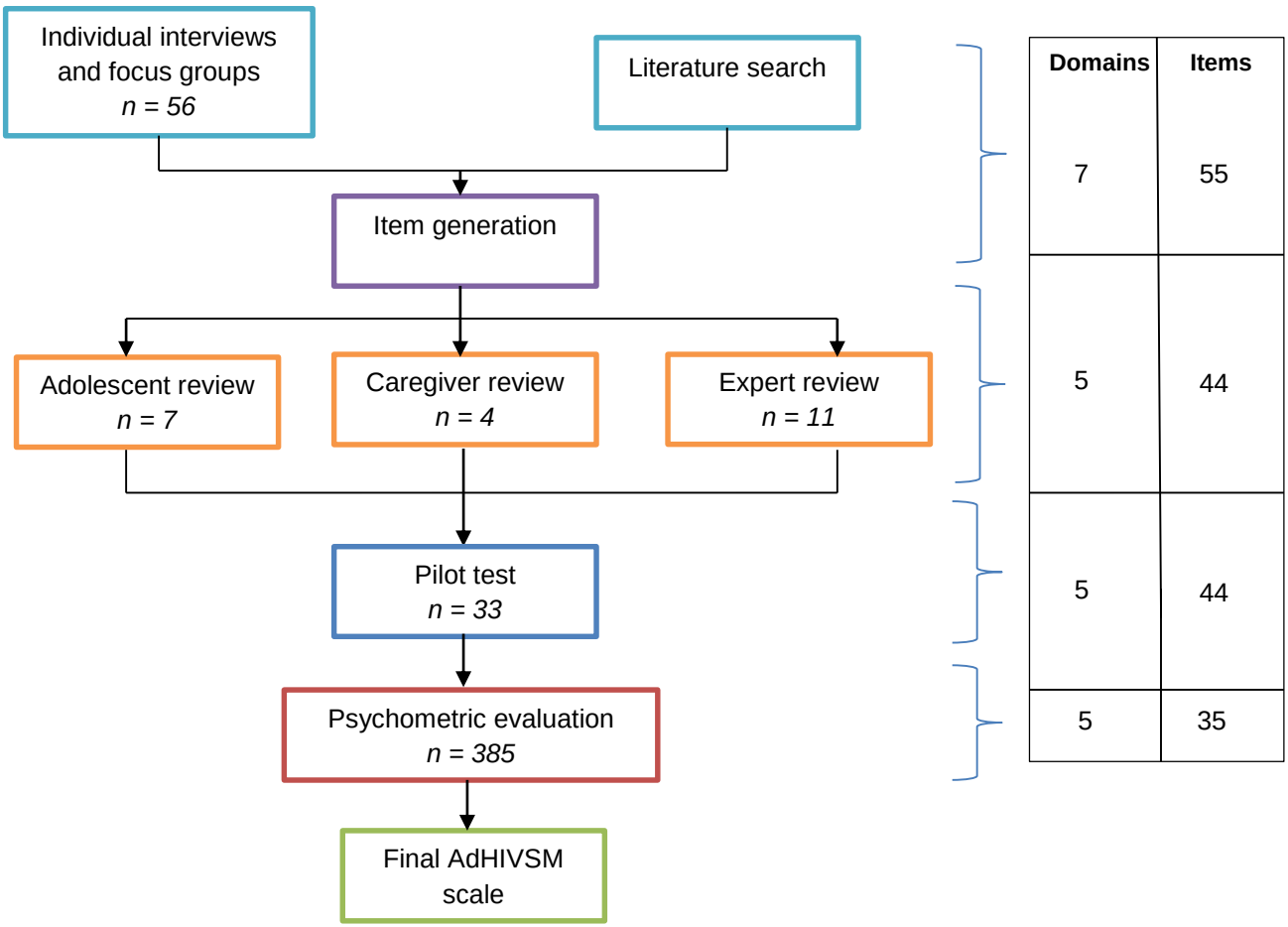

Figure 3.1 Development of the adolescent HIV self-management scale

3.3 PHASE 1: REALISATION OF ADOLESCENT HIV SELF-MANAGEMENT

The objective of the first phase of the study was to explore the realisation of adolescent HIV SM from the perspectives of adolescents, caregivers and healthcare workers. The construct of interest (SM) was conceptualised and SM processes and behaviours that underlie the construct were identified and described (Onwuegbuzie et al., 2010:60). This was achieved through individual interviews with adolescents, caregivers and healthcare workers and focus groups with adolescents.

3.3.1 Research design

Interpretive phenomenology (IP) was used to explore the realisation of self-management from the perspectives of adolescents themselves, caregivers and healthcare workers. The founder of IP is Heidegger (Polit & Beck, 2017:472). Heidegger stressed that the human experience should be interpreted and understood and not merely described (Lopez & Willis, 2004:728) - the ontological being in the world is emphasized (De Witt & Ploeg, 2006:216). The researcher locates the research, the researcher and the participants within their social and cultural world in a transparent way (Greatrex-White, 2008:1842) – acknowledging that multiple realities exist and that understanding and interpretation is a continuously evolving process with no finite end.

IP was appropriate for this study since the researcher explored participants' experiences on adolescent HIV SM, how they attribute meaning to the concept of SM in their unique cultural and historical context and how their lifeworld influenced the decisions they make while self-managing (Larkin, Watts & Clifton, 2008:104; Tuohy, Cooney, Dowling, Murphy & Sixsmith, 2013:20; Chan, Brykczynski, Malone & Benner, 2010:x). The Heidegerrian concept of "situated freedom" means that the decisions of people are influenced by their contexts (their freedom or agency is circumscribed by the conditions of their daily lives) (Lopez & Willis, 2004:729) and interpretive phenomenological enquiry focuses on describing the meaning participants' attach to being in the world and how this meaning influences their everyday choices. There are deeply embedded structures, processes and practices that shape our being in the world which we are often unaware of that the research aimed to uncover (Greatrex-White, 2008:1844). The focus was therefore not only on describing daily SM activities or experiences of the adolescents living with HIV, but on how the community, family and healthcare context influenced these experiences. Exploring Heidegerrian tenets such as lived experience, being in the world, being with, encounters with entities and care structure served to explicate and provide a deeper meaning of adolescent HIV self-management in the study context (Horrigan-Kelly, Millar & Dowling, 2016:7).

IP was also the most appropriate design since it allowed the researcher to draw on her knowledge of the literature and the IFSMT theoretical framework to guide data collection and

analysis, which was useful for the identification of items for inclusion in the instrument. The philosophy that underpins IP is hermeneutics. Hermeneutics presupposes prior understanding on the part of the researcher and views this expert knowledge as a valuable guide to inquiry; therefore, bracketing did not occur, but assumptions and theoretical underpinnings were made explicit (Lopez & Willis, 2004:730; De Witt & Ploeg, 2006:216). The interpretive process involved interpretations of both the participants and the researcher that built over time (Polit & Beck, 2017:472; Conroy, 2003:202). In this process, the researcher engaged with the participant narratives to identify how they viewed the processes and behaviours of adolescent HIV SM, how their views compared with that of the researcher's and with what was described in the literature. The concept "constitutionality" or "fusion of horizons" is related to intersubjectivity and means that the interpretations that the researcher arrives at is a blend between meanings expressed by both the participants and the researcher. Participants' narratives can therefore be interpreted in different ways, but meanings stated in the research findings should be logical, within the study framework and reflect the realities of the participants (Lopez & Willis, 2004:730). Corbin and Straus (1988:1) state in their work on understanding the course and impact of chronic illness, that the research should be both theoretically and interactionally sensitive. This means that the researcher should keep an interpretive distance from the participants while still trying to see the world from their perspective.

3.3.2 Population and sampling

The researcher made use of purposive sampling. In IP, a homogenous sample is obtained to reveal what meaning a particular group of people attach to the phenomenon (Christ & Tanner, 2003:203). The researcher purposively chose a group of participants who had experience of adolescent HIV SM and could provide a thorough understanding of the phenomenon from varied perspectives (individual, family and health system). A "rounded" understanding of the study topic is obtained if the participants (adolescents, caregivers, and healthcare workers), the researcher and the community is included in the research (Conway, 2003:12).

Adolescents who live with HIV were the focal group since their experiences and narrations were used to uncover how SM is realised. Caregivers and healthcare workers were included due to the pivotal role they play in assisting adolescents with SM. The interpretation of how SM is realised is based on the shared understandings of these role-players. The researcher and study supervisors were another group in the hermeneutic circle. The reason for including the researcher(s) in the process was to make explicit any influence they may have on the interpretation of the findings. The community/society forms the last group and contributes to the background understanding of the participants. The community provides the context in which SM processes and behaviours take place – at home, school or in the healthcare

environment. Each of these groups gives meaning to the other and derives meaning from the communal background (Conway, 2003:14; Richie et al., 2014:113).

Adolescents, caregivers and healthcare workers at two urban ART clinics were selected. Urban facilities with dedicated adolescent services were purposefully selected for phase one since the healthcare workers had experience in working with adolescents. The selection of the two facilities was also based on the willingness of the staff to participate in the study. The facilities were an outpatient clinic at a tertiary hospital (Site A) and a community health centre (Site B). These facilities were approximately 40 kilometres apart and served different communities.

To ensure diversity in participant experiences, age, gender and home language were considered as sub-groups and the researcher aimed to include participants in each subgroup (Richie et al., 2014:113; Onwuegbuzie & Collins, 2007:289). Individual interviews provide opportunity and flexibility to explore new issues that arise in more detail. The researcher therefore first engaged in individual semi-structured interviews to identify the possible range of topics to be explored in the focus groups. Individual interviews were followed by five focus groups with 5 to 9 adolescents in each group. The sample for phase 1 is depicted in Table 3.2.

Table 3.2 Sample for phase 1

Data collection method	Participants	Site A	Site B	Total number of participants
Individual interviews	Adolescents	3	3	6
	Caregivers (parent/guardian)	3	3	6
	Healthcare workers	3	3	6
Focus groups	1. Mixed male/female (15 - 18)	9		9
	2. Female (14 - 16)		8	8
	3. Female (13 - 14)		9	9
	4. Male (13 - 14)		5	5
	5. Male (16 - 18)		7	7
TOTAL				**56**

IP usually includes repeated interviews. However, in this study the researcher did not conduct repeat interviews, but rather interviewed adolescent-parent dyads and combined individual interviews with focus groups. Focus groups have been used in several IP studies and Bradbury-Jones, Sambrook and Irvine (2009:663) argue that focus groups can be beneficial

in interpretive phenomenological research, since IP is not concerned with collecting "uncontaminated" participant accounts. Focus groups in this study provided opportunities for participants to share of and reflect on their own and others' experiences, inclusive of clarification and checking for understanding between participants and between participants and the researcher (Bradbury-Jones et al., 2009:667).

Separate focus groups for males and females facilitated the discussion of gender sensitive issues. A study that explored the experiences of adolescents living with HIV in Zambia found that adolescents appeared to be more relaxed and open amongst those of similar age and gender (Mburu et al., 2014:11). The groups were organised based on the established clinic groupings of the adolescents in order to ensure that the adolescents were comfortable to talk freely and to ensure that they were not inconvenienced by coming to the clinic outside their routine clinic visits.

The aim of the focus groups was to provide a thorough exploration of the themes of adolescent HIV SM that emerged. By the end of the interviews and focus groups no new themes related to SM were emerging (i.e. data saturation was achieved). Although the researcher noticed diversity in experiences and contextual factors, the meanings related to SM became redundant.

3.3.2.1 Inclusion criteria

- Adolescents aged 13 to 18 who attended HIV or ART services, irrespective of how they acquired HIV.
- Caregivers (parents or guardians) of adolescents who had been living with the adolescent for at least one year.
- Healthcare workers (doctors, nurses and lay healthcare counsellors) with a minimum of one year experience in working with adolescents living with HIV.

3.3.2.2 Exclusion criteria

- Adolescents to whom their HIV status had not been fully disclosed.
- Adolescents who were unable to meaningfully participate due to any physical or cognitive challenges.

3.3.3 Data collection

Data collection for phase one took place between July and December 2015. The interview guides and procedures used follows.

3.3.3.1 Interview guides

Interview guides with open-ended questions (Appendix 4) were used to guide the data collection. The questions in the interview guides were based on the theoretical framework. They explored the processes of self-management as well as individual, family, community and healthcare contextual factors. The interview guide for adolescents, caregivers and healthcare workers differed slightly. Participants were interviewed in their language of choice (English, Afrikaans or isiXhosa). The researcher is fluent in Afrikaans and English and made use of a trained and experienced fieldworker to interview isiXhosa-speaking participants.

The interviews started with open-ended questions such as: *'Tell me more about yourself'* and '*tell me more about coming to this clinic.*' The interviewer used probing questions and used skills such as active listening, reflection and summarising throughout the interviews and took note of non-verbal cues. Moments of silence were used to allow the researcher and participants to reflect on what was being discussed. The researcher allowed a "play of conversation" that allowed for openness (Smythe, Ironside, Sims, Swenson & Spence, 2008:1392). The researcher monitored how the interview was affecting the participants and noted emotional responses such as avoidance of the topic, awkwardness or distress and responded appropriately.

3.3.3.2 Pre-testing

During the first phase of the study, the interview guide was discussed with the study supervisor and one expert in adolescent HIV care. The interview guide was adapted accordingly. The interview guide questions and prompts were also adapted after the first few interviews as new themes emerged that warranted inclusion. The researcher sat in with the first interview of the isiXhosa-speaking fieldworker to assess her interviewing skills. The researcher and fieldworker also had a debriefing meeting after the first few interviews to discuss any changes to the interview guide.

3.3.3.3 Procedures

Data was collected through individual semi-structured interviews and five focus groups. Participants were purposefully selected by the researcher, with the assistance of healthcare workers at the sites. The researcher informed the healthcare workers at the sites about the study purpose and inclusion criteria. The facility managers at the sites were asked to make recommendations regarding suitable healthcare workers to interview and these healthcare workers were approached by the researcher and a time and place convenient for the participants were scheduled to conduct the interview.

The researcher approached adolescents and caregivers who met the inclusion criteria since the healthcare workers were too busy to inform the participants of the study themselves. This

occurred after their consultation with the healthcare workers or after the adolescent group sessions in a private room at each of the study sites. The study purpose was first explained to the adolescents and the adolescent assent form was given to them. The researcher emphasised to them that taking part in the study was voluntary and that it would not affect their care at the clinic.

Those who agreed to participate were asked to provide the researcher with their contact details (cell phone number) and the contact details of their parent or legal guardian. The researcher also asked their permission to contact their caregiver or legal guardian. Caregivers or legal guardians of willing adolescents where either approached in person (if they accompanied the adolescent) or contacted telephonically and the study purpose explained.

Legal guardians or parents who accompanied adolescents were given the legal guardian consent form and the caregiver participant consent form if they wished to also participate in the study. Adolescents who came to the clinic alone and wished to participate were given a legal guardian informed consent form to take home to their caregivers. Arrangements were then made for when the interviews or focus groups would take place at a time and venue that were suitable for the participants.

Participants received an imbursement of R80 for each interview or for participation in the focus group in order to cover their travel costs and as compensation for their time.

Individual interviews

IP emphasises involving participants in the research process (Conway, 2003:16). This was realised by encouraging participants to choose a venue where they were most comfortable for the interviews or the focus group; allowing them to tell their own stories and by increasing their access to their own narratives by inviting some of the participants to participate in the third phase of the study.

The researcher scheduled a suitable interview time and place for willing healthcare workers after approaching them and obtaining their permission for the interview. All the healthcare workers' interviews were conducted at the study sites at a time when the healthcare workers were not busy, since that was the most suitable to them.

The individual adolescent and caregiver interviews were conducted either at the study site in a private room while they were waiting for their medication at the pharmacy or on another day, at a convenient time and place. Adolescents and their caregivers were interviewed separately. At the onset of each interview, the study purpose was explained again and informed consent was obtained from the caregivers and assent from the adolescents.

A good interview depends to a large extent on the personal and professional qualities of the interviewer (Richie et al., 2014:184). The researcher successfully completed a course in qualitative research methods, including individual interviews and focus groups, and worked under the supervision of the study supervisors. The isiXhosa-speaking fieldworker had experience in qualitative and adolescent-focused research interviewing and worked under the supervision of the researcher, who assessed the quality of the interviews. Data was collected using the semi-structured interview guides (Appendix 4). Individual interviews were recorded with two audio recorders.

In IP the purpose of the interview is to explore the lived experience of the participants and to develop a conversational relationship about the meaning of the experience. Interviews were conducted in a flexible interactive way allowing interviewees to shape the content of the interview (Richie et al., 2014:183). Both the researcher and participant used their background to interpret what was said in the interview (concurrent interpretation) (Conway, 2003:14). This caused a 'ripple effect' that affected further interpretations and changed the understanding of all to a lesser or greater extent. The researcher tried to maintain a natural converstation, using open-questioning and encouraged the participants to reflect on their own narratives. The researcher listened actively to what was being said as well as the participants' mood and non-verbal cues. This was achieved through using verbal and physical ways of communicating empathy and trust such as head-nodding, smiling appropriately, eye contact and use of 'um-hmm'. The researcher contributed by restating participants words, making reflective observations, or asking for clarification in order to draw out what was hidden (Conway, 2003:25). In searching for a deeper understanding and to prevent misunderstanding, clarification questions were used to ensure accurate understanding. The participant could then refute or agree with the understanding of the researcher.

Throughout the interviews and while listening to the audio recordings and reading of the transcripts, the researcher reflected on the interpretive questions that aided the development of the "hermeneutic commentary". These included what lay beneath what was being said, what emotions/body language were exhibited, what was valued by the participant, what was the current context of the situation, why and how the interviewer asked questions and whether the interviewer listened (Conway, 2003:24).

The individual interviews took between 16 minutes to an hour in total. The interviews with the younger adolescents (those who were 13 or 14 years old) were shorter and needed more prompting than with the older adolescents, caregivers and healthcare workers. Interviews were audio recorded and recordings were transcribed verbatim.

Focus groups

Focus groups were used to augment the understanding of the researcher of adolescent HIV self-management obtained in the individual interviews. The focus groups were conducted with different participants than those who participated in the individual interviews. This was done to allow a range of experiences to be tapped and for triangulation between the data collection methods. Focus groups create a more natural environment where participants are influenced by each other (Ritchie & Lewis, 2014:212). Data are generated by interaction between participants. The aim was to elicit a wide range of spontaneous responses and to sharpen and refine individual responses. This was especially appropriate working with adololescents since the group context created a more natural and relaxed atmosphere. Focus groups also reflects social constructuions such as normative influences and collective or individual identity. In IP, a focus group can facilitate interacton and comparison of experiences that may further illuminate the complexities of a phenomenon. Individual experiences can be preserved in a group context, but the researcher should ensure that each participant acquires an opportunity for his or her story to be heard. The facilitator must therefore be skillful in drawing out reticent participants and manage dominant participants in the group (Bradbury-Jones et al., 2009:668).

The researcher and trained fieldworker contacted legal guardians telephonically two days before the focus group to obtain telephonic consent (see discussion under Ethical Considerations) for the adolescent participants under the age of 18 to participate in the study and also asked them to sign the written consent forms that were sent home with the adolescent. Adolescents who provided cell phone numbers were reminded via short message service (sms) two days before the focus groups about the time and venue.

All focus groups were conducted at the clinic or hospital site as this was the most suitable for all the participants. The focus groups were conducted after the usual group sessions at the clinic or after the adolescents were seen by the healthcare workers if there were no group sessions scheduled. The focus group size varied from five participants to nine. The first focus group was a mixed-gender group due to the way the adolescents were grouped by the clinic and the subsequent five groups were male or female only.

At the onset of the focus group, the researcher explained the purpose of the focus group again. Parental/guardian consent was confirmed, and assent was signed by adolescents under 18 and informed consent obtained from adolescents who were already 18 years old. The researcher then again emphasised that their participation was voluntary. Confidentiality of their responses and group confidentiality was explained and emphasised. Refreshments were provided at this stage to ensure a relaxed atmosphere.

Participants had the opportunity to choose pseudonyms for use during the interview which were then written on nametags. They were provided with a printed copy of some of the interview questions and were given 10 minutes to think about the questions and make notes for themselves before the group started.

The group started with the researcher introducing herself and the fieldwoker and explaining their roles. Each member then introduced themselves and provided a background that included their age and their grade in school. Participants were allowed to speak in the language of their choice and the fieldworker or researcher translated the responses so that the whole group could understand the response and for transcription purposes. The opening topic related to what happens at the clinic, in order to create a common neutral ground for participants before asking the questions related to self-management. Participants were encouraged to present their own views, but also to reflect on the views of others and prompted other group members to reveal more. The researcher continuously rephrased questions, summarised what had been discussed and prompted further explanations; while the fieldworker managed the audio devices, took note of non-verbal cues and prompted silent participants to contribute to the group discussion. The duration of the focus groups were between 50 and 102 minutes. The researcher ensured that the adolescents were comfortable and did not become fatigued. Audio recordings were transcribed verbatim.

3.3.4 Data analysis

Verbatim transcriptions of interviews were translated into English where interviews were done in isiXhosa and were compared to the audio recording for integrity. Field notes made by the researcher and reflective notes after each interview were incorporated as part of the data and analysed together with the interviews. This on-going log of field notes tracked the progress and thoughts of the researcher about the research and prompted reflection on implicit assumptions (Conway, 2003:27).

ATLAS.ti Version 7.5. (2016) software was used to code demographic attributes and self-management related themes and sub-themes. The chosen theoretical framework, namely the IFSMT, was used as the primary guide for the interviews including the coding of data.

Data was analysed using the steps of the interpretive process, namely the iterative model for interpretive analysis as described by Christ and Tanner (2003:203-205) and by using the hermeneutic circle, with continual review and analysis between the parts and the whole text. This process included first order (descriptive) and second order (interpretive) analysis which positions the initial description in relation to the wider theoretical, social and cultural context (Larkin et al., 2008:104). Interpretation was expanded through: i) repeated exploration of the

narratives; ii) by connecting narratives; iii) through ongoing researcher notes and logs; and iv) by referring to relevant literature (Conway, 2003:14).

3.3.4.1 Early focus and lines of enquiry

According to Conway (2003:19), this process is called "attending to footprints" (experiences/narratives) and starts with the concurrent interpretation between the participants and the researcher. The researcher reviewed the audio and written texts and developed initial interpretations. Secondly, the researcher wrote notes of what each participant said at "face value". The researcher also kept a personal log capturing meeting dates and other encounters with study participants as well as her feelings and perceptions in order to reveal her background. This promoted an understanding into one's role as a researcher, how it influenced the research process and was examined by the study supervisors.

The first few transcripts of interviews were discussed with the main study supervisor (Christ & Tanner, 2003:203). This included a critical review of the researcher's interviewing skills. Areas that could be explored in more depth, for example, negative self-management such as deliberately or planning not to take treatment were identified and initial interpretation of the data was discussed in order to identify further lines of enquiry or focus areas to guide subsequent interviews. Missing and unclear sections in the transcripts were identified and discussed. The researcher discussed subsequent interviews with the study supervisors if interesting and contradicting information emerged. This early interpretation also guided further sampling in order to adequately explore all aspects of adolescent HIV self-management. For example, the researcher decided to interview at least two participants of each healthcare worker category involved in the care of adolescents since they provided different aspects of care and engaged adolescents on different levels. In the early stages the researcher noticed a difference between younger and older adolescents in the way they could express themselves and their view of self-management and therefore made sure that both younger and older adolescents were represented in the sample. As the researcher started to be immersed in the data, her own understanding of adolescent HIV self-management started to change.

3.3.4.2 Central concerns, exemplars and paradigm cases: engaging with philosophy and theory

In this phase, central meanings and important themes for each participant or group were identified that included personal and environmental factors or life events that may have influenced the participants' experiences.

The researcher re-immersed herself in the data through reading the transcripts and listening to the audio recordings again. In searching for meaning, the researcher through the interpretive process, for example, looked at positive and negative characteristics of situations, systems or role models. Careful attention was also given to emotions and connections made between what is said on the surface and deeper, hidden meanings. Narratives were examined multiple times in an attempt to uncover background meanings and tentative concept-themes were compiled. This process was guided by interpretive writing and it involved making summaries of the central concerns and themes of each participant. These summaries were included as memos in ATLAS.ti and regularly discussed with the study supervisors during interpretive meetings. These early interpretations were rewritten several times.

During this process, exemplars and paradigm cases emerged (Christ & Tanner, 2003:204; Conway, 2003:19). An example of an exemplar in this study was that the adolescent participants viewed taking medication every day as a key component of taking care of their illness. Summaries of exemplars and paradigm cases were discussed with the study supervisors. The naming or coding of exemplars and central concerns were iterative between the researcher and the inputs from the study supervisors. The researcher initially coded a few interviews, which were reviewed by the main study supervisor. The initial code names and list were revised based on the input of the main study supervisor.

3.3.4.3 Shared meanings: thematic development

Phase three concerns finding connections or patterns between meanings within and across participants' stories. Themes are not repetitions of what was said, but an understanding of something that matters significantly and readers are invited to think about these findings further (Smythe et al., 2008:1392). These themes and the interpretation of the themes were discussed between the researcher and the study supervisors.

The study supervisors were provided with the transcripts and had access to the ATLAS.ti folder that contained all the transcripts, reflective notes, interview summaries, codes and code families (themes). Their enacted audit processes contributed to ensuring that the data were adequately interpreted and provided confirmation that the research was performed in line with the study objectives.

The different viewpoints of adolescents, caregivers and healthcare workers were also examined more closely and the contributions of relevant people in the worlds of the participants were noted. This means that the interpretive process spirals outwards and includes examination of the role of others in contributing to the participants' worlds to contextualise the experience (Conway, 2013:19).

Conway (2003:19) further emphasised the identification of paradigm shifts (i.e. instances where one's way of understanding about how to exist in the world and interact in the future had been altered – a turning away from or towards authenticity – a change in values, beliefs or attitudes). An example of a paradigm shift from the study data was that some older adolescents acknowledged that there was a time when they did not take their treatment due to various reasons, mostly that they did not understand why they had to take it. Many of them reported a shift in attitude as they became older towards understanding, accepting and taking control of their situation.

3.3.4.4 Final interpretation

Each subsequent interview and the interpretive notes thereof provided lines of enquiry for past and current narratives as well as future sampling (Christ & Tanner, 2003:204). During this phase, the researcher explored whether any new data emerged that warranted further exploration through interviews. Summaries of the themes and interpretations thereof were finalised once no new data emerged from the interviews.

3.3.4.5 Dissemination of the interpretation

The final phase included refinement of the themes and interpretations with the assistance of the study supervisors. Throughout this process, the researcher kept minutes of each meeting as part of the research log and audit trail. Interpretation remains non-linear and iterative, with the readers of the report making the final interpretation (Christ & Tanner, 2003:205).

The researcher can also develop principles relevant for the situation under study based on the interpretations (Conway, 2003:32). The researcher identified items for inclusion in the adolescent HIV self-management questionnaire that were related to the study framework and the literature in the second phase of the study.

3.3.5 Rigour

The general principles of ensuring trustworthiness such as credibility, transferability, dependability and confirmability were applied to ensure qualitative rigour (Guba, 1981:80) since these principles can also be applied to hermeneutic inquiry (Conway, 2003:33). However, rigour developed for generic application to qualitative research may not be sufficient to express the rigour in IP due to the prominence of philosophy. The underlying assumption of credibility or truthfulness is not consistent with the IP goals of understanding multiple interpretations of the meaning of human experience (De Witt & Ploeg, 2006:222).

Due to the controversy in the literature about what criteria to use when evaluating the rigour of interpretive phenomenological research, both the criteria of Lincoln and Guba (Polit & Beck, 2017:559) and that suggested by De Witt and Ploeg (2006) is discussed below.

3.3.5.1 Credibility

The first measure to ensure credibility is to adopt well-established research methods. The researcher therefore employed qualitative data collection and analysis methods that are widely acknowledged; in addition to continuous support by the study supervisor and co-supervisor who have extensive expertise in the methods of qualitative research.

Early familiarity with the topic and study context was developed through the researcher's involvement in the training of nurses in the management of patients on antiretroviral therapy (ART). The researcher was familiar with the clinical setting where ART was delivered and visited the two study sites where data was collected for the first phase of the study several times before participant recruitment, during recruitment and during data collection.

Preparation for the study was done through training in qualitative research methods, including conducting interviews and focus groups. The researcher had supervised master's students conducting qualitative research in the field of nursing and the fieldworker, who assisted with isiXhosa interviews and the focus groups, also had prior experience in conducting interviews with adolescents and lived in the local community where the study was conducted.

Prolonged engagement occurred through collecting data for the qualitative phase of the study over a period of six months and the utilization of various data sources such as individual interviews and focus groups (data triangulation). This provided the opportunity to test own biases and perceptions as well as those of the participants and to form an understanding of the essential characteristics of the context. The researcher was also able to build trust and rapport with the participants, which in turn assisted in obtaining rich and useful information. The researcher persistently observed the characteristics or aspects of the situation, albeit only in the healthcare context, that were relevant to the study phenomenon through making field notes each time the study sites were visited.

Using a range of participants, including adolescents, caregivers and healthcare workers whereby individual experiences could be verified, ultimately provided for a rich description of adolescent HIV self-management (person triangulation). Site/space triangulation was also employed by including one tertiary hospital and one community health centre. This allowed the exploration of adolescent HIV self-management from adolescents, caregivers and healthcare workers in both settings. Method triangulation was used by using interviews and focus groups.

Several strategies to help ensure the honesty of the participants were employed. Participants had to be willing to participate and they were encouraged to offer their thoughts and feelings freely. The researcher and fieldworker were not involved in the care of adolescents and they were assured that all information will be handled in a confidential manner. Participants were

allowed to contribute their ideas without fear or judgment and could withdraw from the study at any time. Iterative questioning was used throughout the interviews and focus groups in order to uncover possible hidden information, contradictions or deliberate lies. The researcher made an effort to draw attention to similarities, differences and discrepancies in the data within the research report.

Debriefing sessions were held frequently between the researcher, fieldworker and the study supervisors in order to identify alternative approaches and help the researcher to make any assumptions on the part of the researcher explicit. The research was presented at several platforms for peer scrutiny such as conferences during the course of the research project that challenged the assumptions of the researcher and enabled a greater explanation of the research design. In addition, the researcher evaluated the research process continuously through making and reviewing reflective notes. These reflective notes were written during and after each site visit and immediately after an interview or focus group.

Member-checking (participant verification) was done by restating and summarising information during the interview and reflecting with the participants to determine accuracy. Participants then had the opportunity to confirm the researcher's interpretations or provide an alternative interpretation. Another method of member-checking is when participants are provided with the analysed data or report to review its authenticity. The overall goal is to present findings that are authentic and original. Some of the adolescents, caregivers and healthcare workers who participated in phase one were asked to review the relevancy and contextual appropriateness of the themes and items selected for the questionnaire during phase three of the study. They therefore had the opportunity to evaluate the authenticity of the analysed data. According to Conway (2003:33), participant involvement in the research process is one of the ways in which truth value can be incorporated in a hermeneutic study. Harper and Cole (2012:511) report that member-checking also creates therapeutic benefits for participants. The researcher had a similar experience where the participants saw the focus groups in which the item validation was done (phase 3) as an opportunity to discuss issues and ask questions about their disease and treatment.

While writing the research dissertation, thick descriptions were given by making use of participants' verbatim quotations and providing the context in which the research occurred. Constant comparative methods were used to identify within- and between group differences. During the second phase of the study, the research findings were compared to other studies and theoretical frameworks of self-management, further strengthening credibility.

The researcher also used reflexivity strategies by attending continually to her own effect on data collection, analysis and the interpretation of the data (Polit & Beck, 2017:561). This was

accomplished through the maintenance of a log of reflective notes that was completed after each encounter in the study setting or with the study supervisors.

3.3.5.2 Dependability

Dependability (consistency/auditability/stability/reliability) was ensured by providing detailed descriptions of the research methods, including the data collection and analysis (Guba, 1981:80; Polit & Beck, 2017:559).

Data collection included multiple qualitative methods such as interviews and focus groups. In qualitative research, the researcher as the instrument for data collection may change due to error such as fatigue or because of evolving insights and sensitivities (Guba, 1981:81). This "variance" should be clearly explained and the researcher was therefore transparent about any limitations, challenges and changes that occurred during data collection. This occurred through writing reflective notes and sharing the notes with the study supervisors. The process of data analysis, namely coding and the inductive processes of categorising codes were also clearly described. Auditability can be confirmed through comparing the audio recordings against the written transcripts. The study supervisors ensured that the data and the interpretation were genuine. Smythe et al. (2008:1393), however, notes that in Heideggerian phenomenology, the reliability of research statements does not matter as much as how the statements made by the researcher holds the imagination of the readers and provokes them to think and understand.

3.3.5.3 Confirmability

Confirmability or "neutrality" draws attention to the objectivity of the researcher (Guba, 1981:80; Shenton, 2004:72). Strategies used to enhance confirmability are problematic in IP since IP allows the researcher to integrate preconceptions, biases and assumptions explicitly in the research process and findings (De Witt & Ploeg, 2006:222).

Measures employed to limit bias included explicitly stating the philosophical assumptions of the researcher and detailed reflective notes throughout the study. Neutrality was further aided by giving the narrative and interview texts to the study supervisors to read. A data audit trial was kept through a software programme, ATLAS.ti, which was checked by the study supervisors to ensure that the themes and sub-themes accurately reflected the participants' views; and alternative possibilities or explanations were thoroughly explored. The limitations of the study and other factors that may have influenced the data is discussed under the study limitations (section 3.3.6).

3.3.5.4 Transferability

To enhance transferability, a rich description of the study background, setting, target population, research methods and context is provided throughout the dissertation and in the

presentation of the data. The study utilised both interviews and focus groups and involved a large number of participants, contributing to the resonance. The findings were also related to the existing body of literature in the field of adolescence, HIV and self-management. Transferability was further enhanced in the third phase of the study when the participants and other academics were involved in further development of the self-management instrument.

3.3.5.5 Balanced integration, openness, concreteness, resonance and actualisation

Balanced integration was ensured through integrating the philosophical assumptions and theoretical framework in the data analysis process and making sure that there was a balance between the voice of the participants and the interpretation (De Witt & Ploeg, 2006:225).

Reflective journaling about decisions made in the research process assisted in ensuring openness. This is often described in IP research as "opening up the study to scrutiny" and is a systematically explicit process of reflecting on decisions made throughout the study (de Witt & Ploeg, 2006:225).

Thick descriptions of the findings assisted with concreteness and resonance, which can be recognised when study findings position the reader in the context of the phenomenon and connects with experiences from their own life world. The "felt-effect" of reading the study findings of IP is termed resonance. It is a combination of understanding the meaning of the text and understanding one-self (De Witt & Ploeg, 2006:226). Phenomenological interpretation does not end when the study is finished and actualisation implies that it will be interpreted by readers in the future. No formal way to record actualisation exists (De Witt & Ploeg, 2006:226).

3.3.6 Limitations

The threats to the study validity are discussed below as it relates to the qualitative phase and more specifically the IP approach, using the "Qualitative Legitimation Model" (Onwuegbuzie & Johnson, 2006:49). Several threats to internal and external credibility of a research study are identified in this model. These threats relate to the qualitative criteria for trustworthiness as discussed in section 3.3.5.

As discussed before, the term "bias" is not congruent with IP since the assumptions of the researcher and how this influenced the research process and findings is stated explicitly. One possible study limitation is observational bias which occurs when the researcher fails to gain adequate data. Data collection included interviews and focus groups in an attempt to counteract this limitation. Interviews with younger adolescent participants were much shorter

than those with the older adolescents. However, the focus groups helped to elicit more information from the younger adolescents.

Another threat is reactivity, that is, when participants may change the way they respond due to being involved in the research especially when it comes to sensitive topics. The participants had control over what they chose to share and may have been reluctant to share socially divergent behaviours or behaviours that show poor self-management. The researcher, a White female and academic, and the way she interacted with the participants beforehand may also have influenced how the participants responded. The social context of the researcher and the context of the study participants was in many aspects very different. The researcher found herself many times feeling empathetic towards the social and economic circumstances of the adolescent participants. The fact that her social context was different, may have also influenced the way in which she interpreted what the participants said. Eliciting the experiences of various role-players, namely, adolescents, caregivers and healthcare workers, helped to gain a more rounded view of the phenomenon. The focus groups also facilitated normalising some adolescent behaviours, for example, they were initially not eager to admit non-adherence or possible divergent behaviours, but once voiced by one, others agreed that they had had similar experiences.

In the context of IP, Smythe et al. (2008:1393) argues that limitations assume that the research has ended, which is contradictory to IP since it assumes that the process of interpretation continues beyond the research itself. The researcher acknowledges that the uncovering of the components of adolescent HIV self-management may be only one way of interpreting the participants' accounts. There may still be understanding that is hidden. Her own thinking and understanding of the concept continued to evolve beyond the qualitative phase of this study through continued interactions with adolescents, caregivers, healthcare workers, the literature and the supervisors.

3.4 PHASE 2: LITERATURE CONTROL AND ITEM GENERATION

The objective of this phase was to identify items for the instrument by triangulating the data from the qualitative phase, the theoretical framework (IFSMT), existing instruments and the literature. The items generated in this phase and the conceptual definitions are presented in chapter 5.

3.4.1 Procedure

Five main themes were identified during the qualitative phase of the study. The first theme was SM processes and behaviours and this theme had six sub-themes. The themes were first discussed in the light of the literature to gain more insight into the generalizability of the

findings across different contexts and to gather information regarding individual and environmental factors that may influence SM. The researcher particularly tried to identify what aspects of SM would discriminate between adolescents at risk for low SM and those with good SM (DeVellis, 2012:77).

The qualitative findings and the literature were used to provide an initial framework for the items. This was done to ensure that items provided measurement across the breath of the target concept (Patient-Reported Outcome Measurement Information System (PROMIS), 2013:17). The primary theoretical framework used in the study was the Individual and Family Self-Management Theory (IFSMT) of Ryan and Sawin (2009:217). The concepts in this framework were used as a basis for identifying items and the researcher added concepts or components from other frameworks or literature where applicable (DeVellis, 2012:73). Care was taken to ensure that each of the concepts included in this initial framework were also grounded in the study data. The initial item framework consisted of three main sections and seven domains:

- Section 1: Knowing and believing with sub-domains: i) knowing and understanding and ii) believing and valuing.
- Section 2: Self-regulation with sub-domains: iii) self-regulation and problem solving; iv) communication; v) coping with the condition and vi) goals.
- Section 3: vii) Social facilitation and resource utilisation.

For each of the domains, the researcher wrote items based on the participants' narratives, the literature and established self-management instruments. Items were written in a table (refer to Table 5.1 in chapter 5) indicating the domain, the item phrased in a sentence, the supporting literature, related study theme or sub-theme and an appropriate participant quotation. This was done to support the content of the item with the literature and balance it with the participants' narratives. Items were written on an appropriate reading level for the intended respondents, clear, brief, sensitive to choice of tense and person and grammatically well-formed (PROMIS, 2013:17; DeVellis, 2012:81). There were 55 items in the final list.

Finally, self-management and its components were conceptually defined using the framework developed from the literature and the study findings (DeVellis, 2012:74). The researcher produced a conceptual definition for each of the key concepts related to self-management that was grounded in the literature and in the study data.

The items, item framework and conceptual definitions were presented to the study supervisors and their input was integrated and revisions made where necessary. The list of items and definitions were presented to participants during the third phase of the study for review.

3.4.2 Limitations

A possible limitation in this phase was confirmation bias, i.e. the researcher could have produced interpretations compatible with preconceived ideas or the study framework. The researcher tried to keep a balance between the study framework, the literature and the voices of the participants by illustrating the connection between the framework, the literature and the participant narratives. The researcher conducted a thorough literature search of concepts related to self-management and explored various viewpoints of authors in order to adequately understand and describe the concept of self-management. Although the Individual and Family Self-Management Theory formed the basis on which items were developed, several other theories and instruments were consulted. The resonances of the items were further tested in the third study phase when the items were presented to adolescents, caregivers and experts for review.

3.5 PHASE 3: DESIGN AND PILOT TESTING OF THE INSTRUMENT

In phase three, the initial instrument was designed through a review of the items and pilot tested. This phase is discussed in detail in chapter six.

3.5.1 Research design

The research approach used in this study phase was primarily qualitative, utilising participatory methods. This included cognitive interviews with two groups of adolescents and one group of caregivers during which the developed items were presented and discussed. Data generated from the interviews were used to revise the items. Revised items were then presented to a group of experts to examine the clarity and content validity of the items through a modified Delphi survey. The instrument designed with the assistance of the participants was then pilot tested with 33 adolescents in order to identify any additional problems such as inaccurate translation of items.

3.5.2 Population and sampling

During the instrument design phase, the researcher involved key informants including adolescents, caregivers and healthcare workers in the process of item feedback and where necessary, item writing and re-writing occurred.

A purposive sample of participants were selected to participate in three groups to discuss the items. One group workshop was with adolescents aged 13-15, the second with adolescents aged 16-18 and the third with caregivers. A Delphi survey that included email communication was conducted with healthcare workers and researchers/academics (Table 3.3).

Table 3.3 Sample for phase 3

Data collection method	Participants	Site A	Site B	University /other	Total number of participants
Workshop group 1	Adolescents (13-15 years)	2	0		2
Workshop group 2	Adolescents (16-18 years)	4	1		5
Workshop group 3	Caregivers	3	1		4
Delphi survey	Healthcare workers	2	0	1	3
Delphi survey	Academics			9	9
Pilot test	Adolescents	14	19		33
TOTAL					**53**

Some adolescents and caregivers who participated in phase one were asked to participate again in phase three since they were familiar with the study topic. These participants were selected purposefully in order to represent variability in language, ethnicity, gender, age, their ability to communicate in English as a second language and the diversity of themes identified in phase one. Some caregivers could not attend due to work or other family responsibilities. Adolescent-caregiver dyads from both sites were recruited, however, not all the participants attended the workshop on the day (one pair from Site A, and two pairs from Site B did not attend). There were four adolescent-caregiver dyads who participated and three adolescents came alone. One of the caregivers was new and did not participate in the first phase, but was orientated by the researcher before the time and informed consent was obtained. The number of participants was more than the minimum required number of five suggested by PROMIS (2013:2).

The expert group included two healthcare workers who participated in phase one. Ten other participants, either healthcare workers or academics, from different facilities/universities with experience in research on adolescent issues, SM or instrument development were purposively chosen and invited to participate and nine provided feedback. Academics from different disciplines such as nursing, adolescent psychology, paediatrics, HIV management and psychometrics were included. The number of members and mix of roles were selected according to what is prescribed by Polit and Beck (2017:337).

The instrument was then administered to a sample of 33 adolescents for pilot testing. Participants for the pilot test were selected from the same clinics used in phase one. All adolescents who attend the clinic on scheduled appointment days were approached to participate and complete the questionnaire. One adolescent declined to participate. Care was taken to include a minimum of three females age 13-15; three males age 13-15; three females age 16-18; and three males age 16-18; five isiXhosa, five Afrikaans and five English home language speaking participants. The purpose was to assess participants' understanding of the questions and to identify any translation mistakes.

3.5.3 Data collection

The data collection procedures for the workshop, modified Delphi survey and pilot test are explained in this section. Data collection and analysis for phase two took place from March to July 2016.

3.5.3.1 Workshop/focus groups

Items were refined through a focus group using cognitive interviewing techniques to ensure understanding, readability, translatability and literacy (PROMIS, 2013:2). Cognitive interviews are effective for identifying problems in question wording, comprehension and recall and for ensuring items capture the underlying construct. It provides the researcher with a window into the cognitive processes of the participant and proves useful in testing newly developed items (Lippman, Moore, Guzman, Ryberg, McIntosh, et al., 2014:26). As previously discussed in chapter two, the brain of an adolescent is still developing and this means that they may have difficulty comprehending questions, especially if they are about hypothetical situations. They may also interpret questions differently than intended. This, therefore, necessitated the process of cognitive questioning in order to elicit their understanding of items and improve the validity and reliability of items.

Cognitive interviewing is usually done on a one-on-one basis. However, in this study, focus groups were used as an alternative method (Polit & Beck, 2017:336). Since the focus of this phase was still on developing and possibly adding new items and re-wording items or statements, the researcher opted to do the reviewing of items in groups. The focus was on obtaining a range of different viewpoints from young adolescents, older adolescents and caregivers about the initial set of statements.

A workshop was held with two groups of adolescents and one group of caregivers. Domains and self-management processes and behaviours were identified by the researcher in phase two and printed in questionnaire format. During the workshop, each item was assessed for readability, clarity, relevancy, tone and cultural/developmental appropriateness. The participants were asked whether the questions were phrased appropriately and their

understanding of the meaning of each item was discussed. Participants assessed the quality of each item and offered suggestions for improvement to ensure cultural sensitivity (Onwueguzie et al., 2010:64).

The workshop was held on a Saturday and took approximately four hours. The researcher ensured that participants were provided with a tea break and all the participants had lunch before they left. Participants received an imbursement of R80 in order to cover their travel costs and as compensation for their time. Each group had a facilitator and the young adolescent group had an additional facilitator to assist with language translation. The facilitators were either fluent in English and Afrikaans or English and isiXhosa. Participants were encouraged to use any language they felt comfortable with and the facilitators translated to the rest of the group as needed.

Participants were presented with the items/statements in a questionnaire format. The statements were divided into seven sections: i) knowing and understanding; ii) believing and valuing; iii) self-regulation; iv) communication; v) coping; vi) goals; and vii) social facilitation (see chapter 5). The procedure involved presenting one section at a time, asking the participants to answer the questions individually and then rating the list of questions from most important to least important. The item rating scale used was 1=no, certainly not; 2=no, probably not; 3=yes, probably; 4=yes, certainly. For the “goals” domain, the scale used was: 1=never a goal; 2=sometimes a goal; 3=definitely a goal; 4=I’ve met this goal. After the participants individually answered and rated the questions, cognitive questioning was performed in the group. The process was repeated for each of the seven sections.

Cognitive interviews are used to elucidate the underlying processes of response selection. It can be done through a series of structured probes or “think-aloud” methods that allow participants to explain how they interpreted a question and arrived at the response (Polit & Beck, 2017:336). During the cognitive questioning session, participants were asked what they understood by each item/statement presented to them and if they thought the questions were clearly phrased. They were given the opportunity to suggest how statements can be rephrased where necessary. Participants were also given the opportunity to discuss their answers to the questions and state their reasons for giving a particular answer. The facilitator further asked participants what the most and least important items were for them and why. Finally, the participants were asked if they felt that the list was incomplete, i.e. if there were any important things left out in each section. Allowance was made for new self-management processes or behaviours if the participants felt they needed to reword or add new items or behaviours. The process was led and monitored by the facilitator in each group. Facilitators made notes of the qualitative responses regarding the question format and comprehension and sessions were audio recorded.

Participants were also allowed to comment on the clarity of the measuring scale and they were asked to rate the importance of items within each section. The researcher made changes to the statements as suggested by participants and clearly documented the process and changes made. The researcher also reordered the statements within each category from most to least important as decided by the participants. Where advised, new statements were added to the list. A total of 10 new items emerged that were added to the list of items. These were not completely new items, but related to the items already in the questionnaire, e.g. separating items that addressed more than one issue or expanding on some items. This resulted in a final list of 65 items. Participants agreed that the items listed were important components of living with HIV and therefore the researcher did not see a need to conduct additional interviews to explore more themes. The findings of this process is provided in section 6.3.1 of chapter 6.

3.5.3.3 Delphi survey

The researcher initially anticipated doing a third workshop with academics and healthcare workers in order to further evaluate the items. The purpose of this phase was to present the items to academics and healthcare workers for content validation following changes made by the adolescents and caregivers. Due to the busy schedules of healthcare workers and academics, the researcher emailed the items to 12 participants. They were then asked to, on a separate questionnaire, rate each item's clarity and relevancy. They were also asked to provide qualitative comments on each item. Definitions of key concepts were provided in order for them to evaluate if the items fully tapped the underlying constructs. Of the 12 participants, 11 provided feedback.

A Delphi survey involves asking a panel of experts to complete a questionnaire regarding their judgements about a topic of interest (Polit & Beck, 2017:244). Experts assessed the clarity and relevancy of each of the items on a scale of 1 through 4. Key issues that were addressed in the evaluation were whether the items were relevant and appropriate in terms of the construct, whether all the items together measured all the dimensions of the construct, whether the items were culturally and developmentally appropriate, and on an appropriate reading level.

Items were revised or excluded based on the criteria described in the data analysis section below. Due to acceptable content validity results during the first round of review, a second round of review was not necessary. A discussion of the content validity of items are presented in section 6.3.2 of chapter 6.

The revised list of items included in the final Adolescent HIV Self-Management (AdHIVSM) instrument (refer to Table 6.2 in chapter 6), as well as the indexes for clarity and content

validity were circulated back to all the experts for their final input and feedback. Two experts replied with minor comments on the final list of items and they were incorporated.

3.5.3.4 Assembling, item translation and final instrument design

Items were arranged in a logical way in terms of the construct being measured and the response-options provided. All items that related to taking ART were grouped together. Clear administration instructions were provided.

Following the validation of the items, demographic data and other previously validated scales (see section 3.6.3.1) were included in the adolescent instrument. Data regarding risk and protective factors as identified in the theoretical framework were included: age, gender, caregiver educational status, family structure (e.g. orphan), comorbidities (e.g. depression, ADHD, tuberculosis), duration of ART, substance use and current illnesses/symptoms etc. This data were used to account for the contextual influences as described in the theoretical framework.

The researcher made use of the services of an expert in form and communication design from the Stellenbosch University Language Centre to develop the final layout of the questionnaire. This process ensured that the form was in a participant-friendly format and appropriate for the target audience.

The complete instrument, including the other measures, was first sent for language editing and to confirm that the language is on a grade 6 reading level. The Flesch-Kincaid grade level score calculated in Word was 6.5. In addition, the researcher ensured that the examples used in other instruments were context appropriate. The instruments were then translated into Afrikaans and isiXhosa. The translation of instruments included forward translation by one translator, backward translation by another translator, and comparison of the translations (reconciliation) with the original text by a third translator. Discrepancies in the back translation and harmonisation/reconciliation of the translations were resolved between the three translators. This was done to ensure equivalent measures. The KIDSCREEN-27 (measure for health-related quality of life) had to be translated following the requirements of the KIDSCREEN group (KIDSCREEN, 2004) which included forward translation by two independent translators, reconciliation of the two forward translations, backward translation by a third translator and final harmonization.

The researcher and two isiXhosa home-language speaking fieldworkers checked the final translated Afrikaans and isiXhosa documents and identified some minor mistakes which were corrected before pilot testing. Due to the rigorous process of translation, the length of the questionnaire and the high workload of the language translators, the translation process took approximately five months (August to December, 2016).

3.5.3.5 Pilot testing

The developed AdHIVSM questionnaire and the other measures were then piloted. Adolescents who met the study inclusion criteria were approached at the two sites where the researcher collected qualitative data in phase one. Due to the time period between the initial data collection for the qualitative phase (July to December, 2015) and the time of the pilot study (January to February, 2017), the researcher included all adolescents willing to participate irrespective of whether they participated in the first phase of the study. Most of the adolescents who participated in the first phase of the study in 2015 did not remember or recognize the researcher.

Adolescents who were willing to participate signed an adolescent assent form. They provided the contact details of their caregivers in order for the researcher to obtain telephonic consent for their participation. Participants were provided with a R30 food voucher for participating in the study after completion of the questionnaire.

The research trained two isiXhosa/English-speaking fieldworkers (one male and one female) and two Afrikaans/English-speaking fieldworkers (one male and one female) to assist with data collection. These fieldworkers supervised questionnaire completion by the adolescents and assisted the adolescents when they had questions. They checked whether the adolescents completed all the questions. Privacy was ensured by allowing adolescents to complete the questionnaire in a private room in the clinic or hospital. The fieldworkers signed a confidentiality agreement. The researcher timed the completion of the questionnaire, supervised the entire process and assisted participants where needed.

After completion of the questionnaires, the participants were briefly interviewed about their understanding of the items and whether there was anything unclear to them. The purpose of the pilot test was to peruse participants' responses to see if response patterns suggested the need for item changes in the SM measurement (Polit & Beck, 2017:268) and to help clarify problems or translation discrepancies in the other parts of the questionnaire.

Some preliminary item analysis was done. Item analysis examines whether each item serves the purpose for measuring the construct. It also helps to determine whether items discriminate between good and poor performing participants, and what the shortcomings of an item are (Foxcroft & Roodt, 2009:72). Item changes and reasons supporting the changes were clearly documented throughout the process.

3.5.4 Data analysis

3.5.4.1 Workshops

The group discussions/cognitive interviews were audio recorded. Targeted transcriptions were made of the responses and comments of the participants. These summaries were submitted to the study supervisors and a debriefing session was held to discuss the findings. The focus was to identify any comprehension or clarity issues and whether the questions and response options were understood as intended. The reasons provided by participants for choosing a particular answer were reviewed to assess whether they recalled information to be able to select a response that matched their experience. Where problems were identified (especially those reported by more than one participant or group), the researcher, together with the study supervisors explored ways in which the item could be improved or whether the item should be removed.

Responses on the questionnaire items and the item rating were entered into IBM Statistical Package for the Social Sciences (SPSS), version 23 (IBM Corp, 2016). A Cronbach alpha was obtained for each of the categories and for the whole instrument. Average item ratings were calculated to indicate the importance of items within categories. Item scores were also compared for the four adolescent-caregiver dyads who attended. Due to the small sample size, the quantitative measures were however of little value and is not reported in chapter 6.

The qualitative findings of the adolescent and caregiver groups were compared and the differences and similarities are discussed in chapter 6.

3.5.4.2 Delphi survey

The researcher established the measure of agreement between individual participants' responses by using the content validity index (CVI) for items (I-CVI) and the scale CVI (S-CVI) as described by Polit and Beck (2017:311). In order to establish content validity, a panel of content experts rated each scale item in terms of its relevance to the underlying construct. Item ratings were on a 4-point ordinal scale (therefore avoiding a neutral midpoint). The scale was from 1=not relevant through 4=highly relevant. I-CVI is computed as the number of experts giving a rating of either three or four divided by the number of experts. An I-CVI of higher than 0.78 is recommended when six or more experts are used. Items with low ratings should be deleted or revised. This process should continue until each item/statement has an I-CVI of 0.78 or more. The level of agreement was therefore set at a minimum of 0.8 or 80% for each item (Polit & Beck, 2017:311).

During the initial relevancy ratings, only two items had an I-CVI of 0.78. These two items were eventually removed. A further nine (9) items had an I-CVI of 0.8, of which 7 items were removed and two retained. An explanation of why these two items were retained is provided

in chapter 6. All the other items had an I-CVI of 0.9 or 1.0. A second round of feedback regarding item relevancy was therefore not needed.

The S-CVI is defined as the proportion of total items judged content-valid and is calculated by averaging the I-CVI value since it puts the focus on the average item quality. The guideline is that the S-CVI/Ave should be 0.90. I-CVI and S-CVI/Ave are reported separately as advised by Polit and Beck (2017:338). The S-CVI/Ave of the scale was 0.94 and therefore confirmed the content validity of the initial 65 items. The S-CVI/UA, or the proportion of items on a scale that achieved a relevance rating of 3 or 4 by all the experts was 0.57. Acceptable values for S-CVI/UA are not clear, but seems to be close to 0.6. A more detailed report is provided in chapter 6.

In addition to rating item relevancy, experts also rated item clarity from 1=very unclear to 4=very clear. An item clarity score was calculated and all items with an item clarity of less than 0.8 were removed. Eight items had a clarity rating of below 0.8 (these items were dropped) and another eight items had a clarity rating of 0.8, of which two items were removed and the other six revised.

The researcher and the study supervisors evaluated both the item relevancy, clarity and the qualitative feedback from the experts when deciding to revise or remove items. This resulted in revising the language of several items and removing a total of 21 items from the list. The final list included 44 items. The measurement scale was also slightly revised based on the feedback of the experts.

3.5.4.3 Pilot test

Thirty-three participants completed the questionnaires in the pilot test. The primary purpose of the pilot test was to assess the initial reliability of the developed AdHIVSM measure (therefore the need to sample at least 30 participants) and to establish if there were any problems with the translation or participants' understanding of items.

Qualitative feedback from participants and fieldworkers were recorded in field notes and this assisted the researcher in revising items where needed. Cronbach alpha was used to measure the internal consistency within the categories of the developed AdHIVSM instrument as well as for the whole instrument. The preliminary reliability value for the whole scale was above the minimum required value of 0.7 (Polit & Beck, 2017:229) and are reported in chapter 6. The reliability of the other scales in the questionnaire such as the *Treatment self-efficacy* scale and the *Health-Related Quality of Life* scale were also computed and reported.

Preliminary item analysis included assessing the scoring of the developed AdHIVSM instrument items, item-scale correlations, item variances and item means (DeVellis, 2012:105-

107). Inter-item and item-scale correlations and the appropriateness of the scoring of items with negative correlations to other items or the scale, were assessed. The item means and variances were assessed and items with low variances and means close to the upper or lower border of the item scale were identified. Items with variances close to 0 do not discriminate among participants with different levels of the construct and a mean close to the centre of the range of possible scores is the most desirable (DeVellis, 2012:107).

Discriminating power of an item was determined by the item-total correlations and the discrimination index. A positive item-total correlation indicates that the item discriminates between participants who score high or low on a measure. An item-total correlation close to 0 indicates that the item does not discriminate between high and low total scores and a negative correlation indicates poor discriminatory power. Correlations of 0.2 are considered to be the minimum acceptable discrimination value to use when it comes to item selection. The discrimination index was computed by comparing the upper 25% of the sample with the bottom 25% of the sample's performance on an item. If the item is a good discriminator, more people in the upper group will answer the item positively (Foxcroft & Roodt, 2009:78). The results of the item analysis are reported in chapter 6.

3.5.5 Rigour

Reliability and validity are two concepts central to psychological measurement. The purpose of instrument development is to produce an instrument that is valid and reliable.

The content and face validity of the developed AdHIVSM instrument was ensured by developing the items through a rigorous process of gathering qualitative data, the literature and further feedback from participants (DeVellis, 2012:60-61). Criterion-related and construct validity were assessed in the fourth phase of the study.

A preliminary assessment of the internal consistency reliability of the developed measure was made by computing Cronbach's coefficient alpha as discussed in 3.5.4. Temporal stability or test-retest reliability was investigated in the fourth phase of the study.

3.5.6 Limitations

Not all the participants who were invited to provide feedback on the developed items could participate due to being unavailable at the time. Only two young adolescents, five older adolescents and four caregivers participated in the workshop. A larger sample may have yielded more feedback on the items. Performing the cognitive interviews in a group may have caused some participants not to respond truthfully due to group pressure and may have hindered deeper analysis of individual cognitive processes.

Due to the lack of time, many experts did not review the final list of revised items. Although a second round of expert review was not needed since the content validity indexes of the first round were adequate, such review may have provided confirmation that the revision of items to improve their clarity was adequate.

3.6 PHASE 4: ITEM ANALYSIS AND VALIDITY AND RELIABILITY TESTING OF THE INSTRUMENT

During the fourth phase of the study, the revised instrument was field-tested in a larger sample for validation.

3.6.1 Research design

A quantitative cross-sectional survey was conducted. Selected adolescents completed the instrument at one of their routine clinic appointments. The main aim of this phase was to assess the psychometric properties of the developed AdHIVSM instrument. Factor analysis was conducted to further establish construct validity. In addition, the cross-sectional design offered an opportunity to describe the study population and test theory components of the study framework. This also allowed the researcher to determine to what extent the quantitative findings expanded on the qualitative data. The findings are discussed in chapter 7.

3.6.2 Population and sampling

The anticipated sample size for this phase was 440 based on a maximum case to variable ratio of 1:10 (Polit & Beck, 2017:339). However, due to difficulty in accessing the target population, a final sample of 385 was obtained. The sample size was determined to be adequate since it was larger than 300 (DeVellis, 2012:102; Polit & Beck, 2017:339). An assessment of the suitability of the data for factor analysis indicated a significant Bartlett's test of sphericity ($p=0.00$) and a Kaiser-Meyer-Olkin (KMO) index of above 0.6 (Pallant, 2016:184).

This sample size was also sufficient for two tailed hypotheses testing (Onwuegbuzie & Collins, 2007:288). A power analysis of this sample indicated a probability of more than 80% for making the correct decision if the alternative hypotheses were true. The sample size was calculated using an electronic sample size calculator (Clinical and Translational Science Institute, 2016). Based on a previous study by Webel et al. (2012:6) that indicated correlations between self-management and baseline self-efficacy ($r=0.34$, $p<0.01$), social capital ($r=0.18$, $p<0.01$) and ART adherence ($r=0.18$, $p<0.01$), the expected correlation coefficient was set at $r=0.18$ at a confidence level of 95%. A minimum sample size of 240 was needed (Appendix 13).

Adolescents were sampled from selected ART clinics/healthcare centres that provide care to adolescents in the Cape Metropolitan district. Healthcare facilities in the Cape Metropole are either managed by the Provincial Department of Health or the City of Cape Town municipality. Health facilities were included for selection if the total estimated number of adolescents on ART exceeded 50 to ensure that there were a sufficient number of adolescents to participate in the study. The actual number of adolescents between the ages of 13 and 18 remaining in care for each facility had to be calculated by accessing the ART database, Tier.Net since the Department of Health does not collect the statistics routinely. This data was requested from the Department of Health.

There were 10 facilities (excluding the facilities used in phase 1) that had more than 50 adolescents on ART. Initially there were 16 clinics with more than 50 adolescents based on the data received from the Department of Health. However, the list was given to the City of Cape Town to confirm the numbers in the City clinics and the numbers of adolescents remaining in care was reduced. Initially 11 City of Cape Town clinics had more than 50 adolescents listed. However, after the data was reviewed, only two City of Cape Town clinics were included. Of the 10 healthcare facilities that were approached for inclusion in the study, permission was obtained from eight facilities and two facilities Nolungile Community Day Centre (CDC) and Kraaifontein CDC refused, since these facilities apparently did not treat adolescents. To ensure adequate numbers for recruitment, the researcher requested approval from an additional three City of Cape Town sites that had at least 40 adolescents in care. The total number of sites was therefore 11. Due to these three sites being added later, fewer participants could be recruited at these sites (Table 3.4).

The most feasible sampling method was consecutive sampling since most adolescents only attended the clinic every two months. Some of these appointments were clinical, which required the adolescent to be present, but they could send someone to collect treatment for them on pharmacy appointments. This limited the access the researcher had to the study population. All adolescents who attended the selected sites were therefore approached and screened for inclusion in the study until the number of adolescents at a particular site was reached. At some of the sites the required number was not reached even though the researcher and fieldworkers engaged in various efforts to increase recruitment. Recruitment started 13 March 2017 and continued until 4 August 2017.

In total, 467 adolescents were approached; 385 completed questionnaires; 42 refused or were in a hurry; 27 were not eligible (they were not fully disclosed to or were unsure why they are taking treatment; or a few parents thought they would not be able to comprehend questions due to being ‘slow’); from four (4) parental/guardian consent could not be obtained; and 10 did not complete the whole questionnaire/discontinued.

Table 3.4 Sample for phase 4

Clinic number and name	Population based on data received (N)	Estimated sample (62% of N)	Number approached	Final sample (n & % of total sample)
1: Crossroads Community Day Centre	113	70	86	78 (20.3)
2: Khayelitsha (Site B) Community Health Centre	126	78	82	71 (18.4)
3: Delft Community Health Centre	59	37	44	43 (11.2)
4: Eerste River Hospital	51	32	53	40 (10.4)
5: Mitchells Plain Community Health Centre	53	33	41	34 (8.8)
6: Helderberg Hospital	53	33	41	30 (7.8)
7: Wallacedene clinic (City of Cape Town)	57	35	36	30 (7.8)
8: Kuyasa CDC (City of Cape Town)	72	45	23	20 (5.2)
9: Site C Youth clinic (City of Cape Town)	45	27	18	16 (4.2)
10: Site B Youth clinic (City of Cape Town)	38	24	19	14 (3.6)
11: Dr Ivan Toms clinic (City of Cape Town)	44	26	16	9 (2.3)
TOTAL	**711**	**440**	**467**	**385**

3.6.3 Data collection

Data was collected by the researcher with the assistance of trained fieldworkers through paper-based self-completion questionnaires.

3.6.3.1 Instruments

Several questionnaires or scales were used in the study and will be described below. The measures are depicted in Table 3.5 according to the component in the Individual and Family Self-Management (IFSM) theoretical framework it intended to measure.

Table 3.5 Measures used in the questionnaire based on the components of the IFSM

Context	Process	Proximal outcomes	Distal outcomes
• Biographical data: individual, family and condition-specific factors • Symptoms • Medications • Healthcare provider and general satisfaction with healthcare • Stressful life events • Strengths and difficulties (SDQ) • Stigma (HSSC-8)	• ***AdHIVSM-processes*** • HIV treatment self-efficacy (HIV-ASES) • Parental involvement *(removed following the pilot test)* • Resilience (CYRM-12)	• ***AdHIVSM-behaviours*** • Treatment adherence • Sexual behaviour • Substance use • Clinic attendance record	• Health-related quality of life (KIDSCREEN-27) • Viral load

The components of the final questionnaire consisted of 12 sections (Appendix 9). Each of these sections is discussed separately.

Section 1: Background information (Questions about you, your family, your health)

This section contained 22 questions related to the individual, family and health background of the adolescent. Questions included gender, age, home language, highest grade completed and with whom the adolescent was residing. HIV-related information included how they became infected with HIV, when they were diagnosed with HIV, the age of disclosure, other health conditions (co-morbidities) and knowledge of their current CD4 count and VL. These questions were important since it related to the following contextual factors: individual, family and condition-specific.

Section 2: Symptoms (Your symptoms)

This section contained a list of 12 symptoms adapted from the Patient Care Committee and Adherence Working Group of the Outcomes Committee of the Adult AIDS Clinical Trials Group (AACTG) Adherence Questionnaires (Chesney, Ickovics, Chambers, Gifford, Neidig, Zwick & Wu, 2000). The original list included 20 symptoms. The list was shortened to include the most relevant symptoms as suggested by clinicians in the study setting. An additional question was added asking participants to list any other symptoms if they had any. Response options included: I don't have this symptom=0; It doesn't bother me=1; It bothers me a little=2; and It bothers me a lot=3.

Section 3: Medications, treatment adherence and treatment self-efficacy (Your treatment)

This section asked whether the participant was on medication and for how long; or if they had started and stopped taking medication. It included a list of medications where participants could select the medications they are on (that was later removed following the pilot test), how many tablets they take per day and how often they have to take their treatment. These questions related to their knowledge of their own treatment regimen and the treatment complexity.

Treatment adherence (How are you taking your medications?)

Reported treatment adherence was measured with several questions from the literature since there is no single standardized instrument to measure adherence. All of the questions listed below have been used before in research studies.

Barriers to adherence: Participants were given a list of 17 reasons why they might have missed taking their medications within the past month. This list of reasons for non-adherence was taken from the AACTG Adherence questionnaire (Chesney et al., 2000) that was adapted for adolescents in 2004 by the Paediatric AIDS Clinical Trials Group (2016). Response options included: Never=0; Not often (1-2 times per month)=1; Sometimes (1-2 times per week)=2; and Often (more than 3 times per week)=3.

Recall of missed doses: One question comprised a 7-day recall of missed doses (Chaiyachati, Hirschhorn, Tanser, Newell & Barnighausen, 2011:163; Usitalo et al., 2013:107).

Likert scales: Two Likert scale items were used. It included a rating of how often medication was missed over the past month and a rating of when was the last time the participant missed taking medication (Naar-King, Frey, Harris & Arfken, 2005; Chaiyachati et al., 2011:163; Usitalo et al., 2013:107).

Chaiyachati et al. (2011:163) tested five adherence questions (Visual Analogue Scale, Likert scales and recall of missed doses) in rural South Africa in adults and found that the Likert item performed the best for predicting immunologic failure. However, the questions performed poorly in identifying patients with treatment failure. A study done in the United States of America and Puerto Rico by Usitalo et al. (2013:108) found that lower adherence amongst youth 7-16 years of age (as reported by youth and caregivers) was associated with a viral load of more than 400 copies. Youth also reported higher rates of non-adherence for medications missed in the past week, in the past month and in general over the past six months than caregivers. They concluded that caregiver and youth adherence reports can be used to identify youth at risk for poor adherence.

In addition to the treatment adherence questions, a section was included for participants who started to take antiretroviral medications, but stopped. Three questions were included. Participants were asked when they stopped, how they made the decision to stop and to list reasons for why they stopped.

Treatment self-efficacy (How you are managing your treatment)

Treatment self-efficacy (HIV-ASES) was measured with an 8-item scale (Johnson, Neilands, Dilworth, Morin, Remien & Chesney, 2007:359). Participants were asked how confident they were that they could perform a list of treatment-related activities. The scale ranged from 1=not at all confident; to 10=totally confident. The original 12-item scale was developed and tested in adults in the United States. It has robust internal consistency (ps>0.9) and good test-retest reliability at 3 months (rs>0.7). Johnson et al. (2007:360) further reported that higher HIV-ASES scores were related to lower depression, greater problem-solving skills, social support, general coping, self-efficacy and better ART medication adherence.

Four items from the scale was removed by the researcher since it was not relevant in the adolescent group with current antiretroviral regimens. These items were whether participants were confident that they could: “Stick to the treatment schedule when it means changing eating habits”; “Continue with treatment even if their T-cells drop significantly”; “Continue with treatment if people close to them say it is not doing any good”; and “get something positive out of participation in treatment, even if the medication does not improve their health”. These items all had lower factor loadings as reported by Johnson et al. (2007:369). The final list of 8 items included 7 items on the integration sub-scale and one item on the perseverance sub-scale of the original HIV-ASES instrument. Dr Mallory Johnson was contacted and permission obtained to use and modify the instrument (Appendix 7). She commented that the modifications made sense given the context and changes in HIV treatment (Johnson, 2016).

Section 4: Questions about the clinic/hospital (Your clinic or hospital)

Section 4 included five questions about the clinic or hospital. These were whether the primary healthcare provider was a doctor or a nurse, whether they felt respected by the healthcare provider, were satisfied with services, liked/enjoyed attending the clinic and experienced transport problems to attend clinic/hospital visits. These questions related to contextual factors such as health care access and transportation.

Section 5: Adolescent HIV self-management (Taking care of yourself)

The AdHIVSM scale was developed by the researcher during phase two and three. The scale had 44 items. Items were measured with a four point Likert scale. Two scale options were used: Strongly agree/Always; Agree/Most of the time; Disagree/Sometimes; and Strongly

disagree/Never. Scores ranged from 0 through 3. Three items were reversed scored. The items were not presented in domains, but the researcher initially identified five domains during the questionnaire development stage: Knowing and understanding (11 items); Believing and valuing (3 items); Self-regulation (14 items); Self-management behaviours (11 items); and Social facilitation (5 items) (refer to chapter 5).

Section 6: Life events (Your life events)

This section included 20 questions related to stressful life events (SLEs) that provided further information about the context and environment of the adolescents. This scale had been tested with persons living with HIV in Puerto Rico, South Africa and the United States by Corless, Vos, Guarino, Wantland and Holzemer et al. (2013:478). Corless et al. (2013:478) found that the total number of SLEs correlated significantly with the total number of reported symptoms, adherence concerns and the quality of life of persons living with HIV. A similar list of symptoms is also included in the Revised Quality of Life Assessment for ages 12-20 developed by the Paediatric AIDS Clinical Trials Group (Frontier Science, 2003). Since the 20 items used by Corless et al. (2013:478) were used in adults, the researcher adapted the list of items based on the questions in the Corless instrument and the questions used in the Revised Quality of Life Assessment for ages 12-20 by the Paediatric AIDS Clinical Trials Group.

Section 7: Health-related quality of life (Your quality of life)

Health-related quality of life and well-being was measured with the KIDSCREEN-27 which consists of 27 items and measures health and well-being on a 5-point Likert scale (Ravens-Sieberer et al., 2013:1). The KIDSCREEN-27 has five latent concepts: Physical activities and health; General mood and feelings about yourself; Family and free time; Friends; and School and learning. The scale include response options: not at all/never; slightly/seldom; moderately/quite often; very/very often; and extremely/always. Three items are negatively scored. It is applicable for healthy and chronically ill children and adolescents from 8 to 18 years of age and can be completed by children/adolescents themselves.

According to Ravens-Sieberer et al. (2013:6), the Cronbach's alpha coefficients of the KIDSCREEN-27 subscales ranges from 0.80 to 0.84 and test-retest reliability ranging from 0.61 to 0.74. In addition, it showed good convergent, known groups, and criterion validity. Masquillier, Wouters and Nöstlinger (2012:1) adapted the KIDSCREEN-27 for use in Uganda and Kenya by changing the wording of items and translated it into local languages. They found that the adapted tool was adequate to measure health-related quality of life for HIV-positive adolescents aged 13-17 in low-resource settings, but said that further testing was needed. The Cronbach's alpha's for the subscales were above 0.7.

The researcher obtained permission from the KIDSCREEN group to use the questionnaire and translate it into Afrikaans and isiXhosa following the suggested translation guidelines (Appendix 7). This translation process included forward translation by two independent translators, where after problematic items needed to be reconciled, followed by backward translation into English (KIDSCREEN, 2004).

Section 8: Strengths and difficulties questionnaire (Your strengths and difficulties)

The Strengths and Difficulties (SDQ) questionnaire was originally developed in the United Kingdom as a screening tool for the early detection of children at risk for emotional-behavioural disorders. It is a 25-item measure designed for children aged 3 through 17. It utilise a three-point Likert scale including: not true=0; somewhat true=1; and certainly true=2. Subscales derived from the measure include: Conduct problems; Inattention-hyperactivity; Emotional symptoms; Peer problems; and Prosocial behaviour (Youth in Mind, 2016). Although the use of the questionnaire is permitted, change of the wording of the questionnaire and unauthorized translation is not allowed. The scale has already been translated into Afrikaans and isiXhosa and translated versions were available on the SDQ web page (www.sdqinfo.com). These available translated versions of the questionnaire were checked by language experts in Afrikaans and isiXhosa from the Stellenbosch University Language Centre and several language mistakes were identified. These mistakes were corrected without changing the original meaning of the questions.

Sharp et al. (2014:1174) tested the questionnaire on AIDS orphans in South Africa between the ages of 7 and 11. Internal consistency for the sub-scales varied between 0.26 and 0.84. Their findings supported the use of the questionnaire when completed by a caregiver, but not as a self-report measure. However, the adolescents in the current study were between the ages of 13 and 18 and therefore could probably better report on their own. The developers of the SDQ recommended against the use of self-report in children younger than 11 years (Sharp et al., 2014:1183).

Section 9: Use of alcohol and other drugs (Your use of alcohol and drugs)

This section contained nine (9) questions about the use of alcohol and drugs. These questions were derived from the Youth Questionnaire for persons aged 15 to 24 used in the Third South African National HIV, Behaviour and Health survey (2008) and is available on the Human Science Research Council web page (http://www.hsrc.ac/za).

Section 10: Sexual behaviour (Your sexual behaviour)

This section contained 15 questions about sexual behaviour, particularly vaginal/anal intercourse, the frequency of intercourse and the use of condoms. These questions were also

derived from the Youth Questionnaire for persons aged 15 to 24 used in the Third South African National HIV, Behaviour and Health survey (2008).

Section 11: HIV stigma (How you experience HIV stigma)

This section contained 12 questions related to HIV stigma. Firstly, adolescents were asked with whom they have disclosed their status and whether they were treated differently after disclosing their status. HIV stigma was then measured with the HIV Stigma Scale for Children (HSSC-8) that contained 8 items (Wiklander, Rydström, Ygge, Navér, Wettergren & Eriksson, 2013:195). The scale was developed from a previously validated 40-item HIV stigma in adults with HIV (Berger, Ferrans & Lashley, 2001). The adapted instrument measures HIV-related disclosure concerns, negative self-image, and concerns with public health attitudes. It was tested in Sweden with children aged 8-18. The scale had good internal consistency (Cronbach's alpha=0.81), except with the disclosure concerns subscale. Higher levels of stigma correlated with poorer health-related quality of life (Wiklander et al., 2013:195). Permission was granted by the authors to use the measure (Appendix 7). An additional two items were added to this instrument based on the feedback of experts in phase 3. These two items were more positively phrased compared to the negative phrasing of the other 8 items. A four-point Likert scale was used that ranged from 'strongly agree' through 'strongly disagree'.

Section 12: Resilience (Your resilience)

The Child and Health Youth Resilience Measure (CYRM-12) was used as a brief measure of resilience (Liebenberg, Ungar & LeBlanc, 2013:131). The questionnaire has been tested in Canada and has shown good reliability (Cronbach alpha of 0.84). The authors concluded that the measure showed sufficient content validity to serve as a screener for resilience processes in the lives of adolescents. This measure is available on request from the Resilience Research Centre (http://www.resilienceresearch.org) and is free of charge. A five-point Likert scale was used that ranged from 'not at all' through 'a lot'. Permission was obtained to translate the measure (Appendix 7).

In addition to the abovementioned measures, the medications of the participant listed on the most recent prescription chart, the last VL measure and the number of clinic appointments missed/attended late in the past six months were obtained from the patient's folder.

A section on caregiver involvement and parent monitoring (Involvement of your parent(s) or caregiver(s)) was included in the pilot study of the questionnaire. This section included 14 questions about the frequency of parental or caregiver involvement and monitoring in the life of the adolescent. The questions were derived from a study conducted by Steinberg,

Lamborn, Dornbusch and Darling (1992:1267) about the influence of parenting practices on adolescent achievement. They found that parental involvement in an authoritative (high acceptance, supervision, and psychological autonomy granting) home context is likely to promote adolescent school success. This section functioned as a measure of parental involvement that may contribute to social facilitation. However, this section was removed following the pilot test to shorten the final questionnaire.

The questionnaire with all the sub-sections was translated by experienced translators into Afrikaans and isiXhosa through forward and back translation of all items, response choices and instructions as explained in section 3.5.3.4. Following translation, a comparison of the meaning of items was made through a bilingual expert review (reconciliation) by a third translator. The KIDSCREEN-27 was translated as prescribed by the KIDSCREEN group (Appendix 8). The questionnaire was also piloted in phase three in order to identify any concerns related to the language and interpretation of certain items

3.6.3.2 Pilot testing

The instrument was pilot tested in phase three as described in section 3.5.4.

3.6.3.3 Procedures

The developed instrument and other measures was provided to participants in the form of a self-administered questionnaire (paper-based).

Some study sites had a certain day allocated for paediatric patients and adolescents to attend, while others had no allocated day. Out of the 11 healthcare facilities, two had no peer support groups and nine had support groups. However, at the facilities with peer support groups, not all adolescents were in groups and adolescents attending groups and those not attending groups were recruited. Following a meeting with the facility manager and the ART staff, the most suitable days to recruit patients at each of the study sites were identified. Adolescents who attended the study sites on the scheduled visits were first identified by the clinic staff and then approached by the fieldworkers to complete the questionnaires. At some of the study sites where there was no allocated day, the clinic staff assisted with contacting adolescents and arranged a suitable day for them to complete the questionnaire at the clinic. If this day was not on a regular appointment day, their travel expenses were reimbursed where needed.

Fieldworkers screened participants according to the inclusion criteria for the study. In some cases, the adolescents were not fully aware why they were attending the clinic/hospital and taking treatment. Such cases were referred to the on-site HIV/ART counsellor and not included in the study. Some of these adolescents were as old as 16 years. In a discussion with some of the doctors, it was discovered that they tell participants not to tell anyone about

their status, especially persons they do not know. It may therefore be, that some of the participants excluded from the study did know their status, but did not want to disclose it to the researcher and fieldworkers. In some cases the parent who accompanied the adolescent said that they had not yet disclosed to the adolescent or that the adolescent was in a special school/'slow learner' and would not be able to understand questions.

The fieldworkers discussed the adolescent assent form with the adolescents and they were provided an opportunity to decide whether they wanted to participate. Adolescents needed to sign the assent form and provide the name and contact details of their caregiver. Telephonic consent was obtained from caregivers or in person from those caregivers who accompanied adolescents. The process of telephonic consent was problematic in some cases since the numbers provided by the adolescents were on voicemail or not answered. Adolescents reported that caregivers worked during the day and could only answer the phone in the evenings. In these cases the researcher allowed the adolescents to complete the questionnaire, but telephoned the caregivers after hours. In four cases, parental consent could not be obtained after several attempts to contact the caregiver.

Participants completed questionnaires in an allocated room at the study sites. Fieldworkers were present at all times to answer the questions of the participants and checked the questionnaires before submission. Some adolescents struggled to understand the questions and when investigated further, it was realised that some were 'slow learners' and in a special school. In those cases the fieldworkers read the questions for the adolescent. Certain adolescents preferred the fieldworker reading the questions even if they had no apparent leaning disability. The fieldworkers indicated on the questionnaire whether the participant completed the questionnaire by themselves (n=271, 70.4%), with a little assistance (n=68, 17.7%), or if the fieldworker had to read the questions and complete it with the participant (n=46, 11.9%). On average the questionnaire took about 45 minutes to complete. Two-hundred and twenty participants (57.1%) completed the questionnaire in English; 126 (32.7%) in Xhosa and 39 (10.1%) in Afrikaans. The fieldworkers and researcher noted that those who completed isiXhosa questionnaires took longer than those completing English or Afrikaans questionnaires.

Two adolescents at one of the study sites became emotionally distressed at the beginning of the questionnaire when completing the questions about when they were diagnosed with HIV. These adolescents were referred to the on-site counsellor and discontinued from the study. One of these adolescents returned a month later asking to complete the questionnaire as she was apparently just 'emotional' on the day. Another adolescent became emotional when completing the "any other symptoms" question. When asked, she expressed that she felt hopeless. She did not want to discontinue and she completed the questionnaire. In a

discussion after the questionnaire she said that she did not have anyone to talk to. One parent contacted one of the fieldworkers saying that her child cried when he came home. The parent did not want to disclose her name or the name of the child and the fieldworker asked the parent to arrange a meeting with the clinic counsellor. When obtaining telephonic consent from caregivers, many caregivers used the opportunity to ask for advice or complain about their adolescent's behaviour and voiced several social, socioeconomic and relational difficulties. Since adolescents completed questionnaires in phase four on scheduled clinic appointment days, they only received a R30 food voucher.

The researcher had to locate the folders of participants who completed the questionnaire. This was not challenging if the reseacher was on-site at the time of questionnaire completion. In other cases the folder had to be drawn using the adolescent's name and surname or if available, the folder number. This was problematic since some adolescents may have indicated a different name on the consent form than that on the folder and their folders could not be found. Some adolescents also indicated on the adolescent assent form that they did not want the researcher to access their folder and their decision was respected.

Viral load measures are mostly done yearly, therefore some of the VL results were at least one year old and in some cases the latest VL in the clinic folder was more than a year old. For those adolescents not yet on ART or recently started on ART, a VL was not available at the time.

Clinic attendance or missed appointments were also difficult to judge due to two to three monthly clinic appointment intervals and the fact that parents/relatives called 'buddies' sometimes collected treatment on behalf of the adolescents. It was also difficult to assess attendance in participants that recently started ART or those who had defaulted and recently returned to re-start treatment.

Adolescents who attended the clinic for a second time during the data collection period were approached to complete the AdHIVSM questionnaire again to assess stability/test-retest reliability. The second questionnaire only included the AdHIVSM items and took approximately 10 minutes to complete. We needed to recruit at least 29 particpants based on a sample size calculation assuming a test-retest reliability coefficient of at least 0.5 (Schilling, 2009:232). However, Polit and Beck (2017:339) suggests 50 to 100. The time between completing the first and the second questionnaire was between one and three months since participants were also recruited consecutively. We over-recruited due to the availability of participants and their willingness to participate again and to account for incomplete questionnaires. Sixty-three (63) adolescents completed the questionnaire a second time and received a R30 food voucher.

Following the data collection process, a debriefing meeting was held with the fieldworkers to discuss any difficulties with the questionnaire administration and their experiences related to the process. This meeting was audio-recorded with the consent of the fieldworkers so that the researcher could use the information to reflect on the process.

3.6.4 Data analysis

Quantitative data was analysed with a statistical software programme, Statistical Package for Social Sciences (SPSS) version 24 for Windows (IBM Corp, 2016). The assistance of a qualified statistician was used where needed. Data was entered directly into SPSS and cleaned before any analyses were conducted. A random selection of 10% of questionnaires entered were checked against the original questionnaires for correctness. Where problems were identified, targeted checks of other questionnaires were performed.

Descriptive statistics such as measures of centre and variance for continuous variables and frequencies and percentages for nominal and ordinal variables were used to initially describe the data. This also included reliability analysis of the other scales used in the questionnaire.

Analysis of the developed AdHIVSM scale included basic item analysis and factor analysis (Polit & Beck, 2017:341). The procedures as described by DeVellis (2012:104) for evaluation of items were performed. This included assessing item performance (the scoring of each item, item-scale correlations, item-variances and item-means). All the items had adequate variability and no items were deleted due to low variability. The item on sexual behaviour was excluded from analysis since it was only answered by 120 (31.2%) of the participants. Four (4) items had item-scale correlations below 0.2, but were retained for factor analysis since they seemed to be important items (Polit & Beck, 2017:341). Three of these items were the reverse scored items and according to DeVellis (2012:105) reverse scored items usually perform poorly.

Total missing data ranged from 0-11 (2.9%) for most of the items. Higher missing values were encountered for the section that applied to participants taking ARV's only. One item (item 41) had 23 (6%) missing values since there was a typing error that affected some of the questionnaires and therefore responses to the question had to be excluded.

Following the assessment of item performance, confirmatory factor analysis (CFA) was performed using covariance-based structural equation modelling (CB-SEM) to confirm whether the data of adolescent HIV self-management fitted the theoretical structure developed in the second and third study phases. Partial least squares or variance-based structural equation modelling (PLS-SEM) was used to determine the composite reliability and convergent validity of the sub-scales (Alarcón & Sánchez, 2015:4). CB-SEM using Robust

Maximum Likelihood (RML) estimation was performed with a computer software programme, LISREL 9.0 (Scientific Software International, 2017), and PLS SEM was done with SmartPLS 3.2.6 (Ringle, Wende & Will, 2005). A senior statistician with experience in SEM performed the analysis after using imputation to replace missing values in the dataset. CFA results did not indicate a good model-fit to the theoretical structure and therefore exploratory factor analysis (EFA) was performed to further explore the factor structure.

EFA was performed on the items using the methods suggested by Pallant (2016:193) and DeVellis (2012:154). For EFA, missing values were managed by selecting 'pairwise' deletion, thereby retaining most of the data since it was assumed that missing values were random. EFA was performed using Principal Component Analysis (PCA). PCA identifies component(s) that closely resembles the information in the larger set of items (DeVellis, 2012:148). The suitability of the data for factor analysis was assessed and revealed the presence of correlation coefficients of 0.3 or more in the correlation matrix. The Kaiser-Mayer Olkin (KMO) value was 0.794, exceeding the recommended value and the Bartlett's Tet of Sphericity was statistically significant which indicates patterned relationships between the items and supported the factorability of the correlation matrix (Pallant, 2016:187; Yong & Pearce, 2013:94).

Thirteen factors were extracted with Eigenvalues above 1 that accounted for 56.86% of the variance of the measure. Kaiser's criterion holds that all components with eigenvalues exceeding 1.0 should be retained. However, this can lead to retaining too many factors. Catell's scree test (Catell, 1966 in Pallant, 2016:185) recommends retaining factors above the point at which the shape of the curve of the Scree Plot changes (the elbow). An additional technique that can be used to confirm the number of factors that should be retained is parallel analysis. MonteCarlo PCA for parallel analysis (Watkins, 2000) was used to generate a set of random eigenvalues that was compared with the corresponding criterion values. The Scree Plot suggested retaining five factors whereas parallel analysis indicated that six factors should be retained. When imposing a six factor solution with orthogonal (Varimax) rotation, some components had few items with low internal consistency. Following an iterative process of imposing a four, five and six factor solution, and a discussion with the study supervisors, a five factor solution was decided upon, since it yielded the best internal consistency of the sub-scales and was the most meaningful. This five factor solution explained 34.5% of the total variance of the AdHIVSM measure. Items had factor loadings of at least 0.2 and four items that did not load meaningfully on any factors were removed. Further, four items that lowered the individual sub-scale internal consistency were removed. The final AdHIVSM scale consisted of 35 items in five subscales that seemed to conform to the theoretical framework of the study: Component 1: Believing and knowing (8 items); Component 2: Goals and facilitation (8 items); Component 3: Participation (10 items) and Component 4: HIV biomedical management (4 items); and Component 5: Coping and self-regulation (5 items). CFA of the

final structure indicated a good model-fit. Absolute fit indices determine how well a theoretical model fits the sample data (Schmitt, 2011:310). The indices used were the model Chi-square test, Root mean square error of approximation (RMSEA), the adjusted goodness-of-fit statistic (AGFI) and the Root mean square residual (RMR) as explained in chapter 7.

Coefficient alpha of the identified sub-scales was between 0.547 and 0.761. The Cronbach alpha for the whole AdHIVSM-35 scale (35 retained items) was 0.839 with no items increasing the internal consistency of the scale if deleted.

The instrument was scored by summing responses for each item and dividing the total by the number of items within each sub-scale. This allowed for comparison between components of adolescent HIV self-management, with higher scores reflecting higher levels of reported self-management. Correlations between the subscales of the instrument was performed by computing a reliability coefficient. Test-retest reliability for the total scale and sub-scales was assessed using Pearson product moment correlation and the Intraclass correlation coefficient (ICC).

In order to test the hypotheses, the individual scores of *Symptoms*, *Reasons for missed doses*, *Treatment self-efficacy*, *Stressful life events*, *Health-related quality of life*, *Total difficulties*, *Total strengths* and *HIV stigma* were correlated with the AdHIVSM-35 and sub-scales. Pearson product moment correlations were used to measure the linear dependence between variables since AdHIVSM-35 scores were normally distributed. Appropriate statistical tests, such as the independent t-test or one-way analysis of variance (ANOVA), were used to determine the relationships between self-management and viral suppression, adherence, risk behaviours, background, disease, treatment and healthcare context variables.

3.6.5 Rigour and psychometric testing

The instrument was developed through a rigorous process of establishing its validity and reliability, which is the primary concern of psychometric testing.

3.6.5.1 Validity

There are four types of validity for validation procedures, namely content validity, structural validity, criterion-related validity and construct validity (Polit & Beck, 2017:218; DeVellis, 2012:59; Foxcroft & Roodt, 2009:49).

Content-validity: Content validity was ensured by selecting a set of items that reflected the content domain (DeVellis, 2012:59). Items were generated from qualitative data and an in-depth literature review; co-designing the instrument with adolescents and caregivers; using expert healthcare workers and academics to determine content validity; and the pilot test. The

researcher therefore included various role-players to provide feedback on the items, clearly documented all decisions made about revising or removing items and communicated changes to the experts who reviewed the items (Polit & Beck, 2017:310). These procedures also confirmed the face validity of the instrument.

Structural-validity: Structural validity was investigated by performing CFA and EFA (Polit & Beck, 2017:319).

Criterion-related validity: There are no specific instruments that measure self-management that could be used as a gold-standard. Criterion-related validity, specifically concurrent validity, was therefore assessed by determining the association between the developed AdHIVSM measure and the current biomedical "gold-standard" of VL (DeVellis, 2012:61; Polit & Beck, 2017:311). The criterion in this case was the VL which is measured annually in patients. The viral load log value was correlated with self-management and self-management levels were also compared across groups of being virologically suppressed (VL≤400) or unsuppressed (VL>400). The limitation of using this criterion is that it may not reflect the current self-management of the participant. Questions related to adherence to treatment was therefore also used for testing concurrent validity, since it could be measured at the same time as self-management. It is however acknowledged that these measures may not reflect all the components of self-management since they are primary focused on medication management.

Construct validity: Construct validity, specifically convergent validity, was assessed relative to priori hypothesised relationships (Polit & Beck, 2017:315). The hypotheses were based on repeated assumptions in the literature and the conceptual framework of the study that self-management will improve the clinical health outcomes of adolescents living with HIV as well as predicted associations between SM contextual factors, SM processes, treatment self-efficacy and SM outcomes such as health-related quality of life (Sattoe et al., 2015:708; Ryan & Sawin, 2009:225).

Validity coefficients should be high enough to be statistically significant at the 0.05 level and a value of 0.3 seems to be acceptable (Foxcroft & Roodt, 2009:53). The coefficient of determination is the square of the validity coefficient and indicates the proportion of variance in the criterion variable which is accounted for by variance in the predictor score (Pallant, 2016:138).

Known-groups validity was assessed by determining if the AdHIVSM measure can discriminate between groups of participants with normal, borderline or abnormal behavioural and emotional difficulties and low versus high risk behaviours. The Eta squared was used to determine effect size when comparing groups. Table 3.6 provides a summary of the validity tests performed. The results of the tests are reported in chapter 7.

Table 3.6 Validity tests

Type of validity	Explanation of how it was ensured / tested
Content validity	Developed items from qualitative data and the literature; involved the target population in item development; determined content validity using the I-CVI and S-CVI.
Structural validity	Confirmatory and exploratory factor analysis on the developed AdHIVSM scale.
Criterion-related validity: Concurrent validity	Tested whether the developed AdHIVSM measure negatively correlated with the viral load log value; tested for the difference in mean AdHIVSM scores between participants who were virologically suppressed versus not suppressed. Tested if the developed AdHIVSM measure negatively correlated with *Barriers to adherence*; tested for the mean difference in AdHIVSM scores between participants who were adherent versus non-adherent.
Construct validity: Convergent validity	Tested for a positive correlation between AdHIVSM and *Treatment self-efficacy*, *Resilience*, *Health-related quality of life* and behavioural and emotional *Strengths*. Tested for a negative correlation between AdHIVSM and *Stressful Life Events*, *HIV stigma*, and behavioural and emotional *Difficulties*.
Construct validity: Known groups validity	Tested for the difference in mean AdHIVSM scores between participants with behavioural and emotional *Difficulties* classified as “normal”, “borderline”, and “abnormal”. Tested for the difference in mean AdHIVSM scores between participants demonstrating low versus high risk behaviour (e.g. alcohol use and sexual behaviour).

3.6.5.2 Reliability

Internal consistency of the item responses of all the scale measures was assessed using Cronbach’s alpha coefficient. Values of 0.7 or higher were considered acceptable for group comparisons (DeVellis, 2012:109). Temporal stability of repeated measures (1 to 3 months apart) of the Adolescent HIV SM measure was assessed by computing a Pearson product-moment correlation coefficient and the Intraclass correlation coefficient (ICC) (DeVellis, 2012:53). Reliability values are reported in chapter 7.

3.6.6 Limitations

A threat to internal validity that was relevant to this study is temporal ambiguity. Temporal ambiguity present in all cross-sectional studies since cause-and-effect relationships between the independent and dependent variables cannot be proven (Polit & Beck, 2014:167). In this study hypothesized relationships were examined, but no cause-effect relationships were assumed. With larger samples, small correlations and small differences between groups can be significant and therefore effect sizes were also reported where applicable. Effect sizes in the study were small to medium.

During the data collection phase, social desirability bias may have influenced the responses of adolescents. In addition, instrumentation bias may have occurred (i.e. other instruments/scales may have lacked validity and reliability for the specific study sample). The

researcher used established measures that have been used in similar settings and compared reliability measures of the study sample with previously reported measures to offset this limitation.

The low percentage of total variance explained by the final factor structure of the developed AdHIVSM may indicate that the variance due to measurement error was higher than the variance due to the construct/latent variables. This mean that the developed AdHIVSM structure needs further testing to establish whether this may be due to, for example, inadequate item-grouping, participants' not understanding the items, differences in reasoning when answering or participant fatigue.

Participant selection may have influenced the external validity of the study findings (Polit & Beck, 2014:169). Only adolescents in the Cape Metropole from larger sites were included. In addition, only those adolescents who attended care, were willing and whose parents consented were included in the study. This may limit the generalization of the findings.

3.7 MIXED METHOD LEGITIMATION

Onwuegebuzie and Johnson (2006:56) identified several typologies for legitimizing mixed research that relates to the validity of the findings from mixed-method research studies. Some of the relevant issues concerning the validity of the overall study findings of this mixed-method study will now be discussed.

3.7.1 Sample integration legitimation

When different individuals are involved in the qualitative and quantitative components of a study, meta-inferences when collating both datasets may be problematic (Onwuegebuzie & Johnson, 2006:56). The study used the same inclusion criteria for adolescents in both the qualitative and quantitative phases of the study. The process of conceptualising the construct of adolescent HIV self-management ensured an exhaustive and valid description of the components of self-management through taking the developed items back to the participants and also verifying the validity with content experts. The researcher took care not to make inferences from the qualitative data that was not confirmed in the quantitative data.

3.7.2 Inside-outside legitimation

This is the degree to which the researcher presents both the emic and etic perspectives (Onwuegebuzie & Johnson, 2006:58). The balance was obtained through peer-review by the study supervisors. The emic perspective is further justified through member-checking as was implemented in the third phase of the study.

3.7.3 Weakness minimization

The researcher consciously assessed the extent to which the weaknesses from one approach can be compensated by the strengths of the other. In this study, an instrument was developed and several other guidelines related to instrument development was incorporated and integrated to strengthen the qualitative and quantitative components of the study. The use of qualitative methods at the initial stages of instrument development to ensure contextual and cultural appropriateness, followed by quantitative approaches to refine and validate the instrument is well-documented in the literature as a rigorous method to develop an instrument.

3.7.4 Sequential legitimation

In the case of instrument development, the sequencing of the qualitative and quantitative phases is not a threat to legitimation since the conceptualization of a construct through qualitative research followed by quantitative testing is well-described in the literature. Therefore, the study design necessitated data to be collected sequentially.

3.7.5 Paradigmatic mixing legitimation

Onwuegebuzie and Johnson (2006:56) suggest that one solution to combine viewpoints in a study is to have a pure qualitative and quantitative part based on pure assumptions and then making meaning from considering the two components of the study. In this study, the researcher tried to stay true to the assumptions of IP in the first phase of the study due to its many competing dualisms with the post-positivistic paradigm. The instrument development process and the influence of the researcher's assumptions were also evaluated in the final chapter of the study.

3.7.6 Multiple validities

This means that both qualitative and quantitative validity issues are addressed appropriately for each study phase, allowing for strong meta-inferences. In each of the study phases, an in-depth discussion about validity was provided. In addition, the threats to validity in each of the study phases were identified.

3.8 ETHICAL CONSIDERATIONS

Ethics approval was applied for from the Faculty of Medicine and Health Sciences Human Research Ethics Committee (HREC) at Stellenbosch University (S15/03/054) (Appendix 1). Permission to conduct the research was further obtained from the Provincial Health Research Committee of the Department of Health in the Western Cape (WC_2015RP53_21), the City of Cape Town (ID No: 10540) as well as from the managers of the selected facilities (Appendix

2). Managers and facilities as well as all the participants were provided with information letters to explain the purpose of the research, including that participation was voluntary and they had the right to withdraw without any negative consequences.

Written informed consent was obtained for participation in the study from healthcare workers, academics, parents/caregivers and legal guardians of adolescents. Assent was obtained from adolescents on a separate assent form in order to comply with stipulations in the South African National Health Act (No. 61 of 2003) (Appendix 3).

During the initial data collection phase the researcher noticed that many adolescents attended the clinic on their own and when provided with consent forms to give to their parents, most failed to bring the forms back. The researcher then applied to the Stellenbosch University Health Research Ethics Committee for an amendment to the initial protocol in order to obtain telephonic consent from the parents or legal guardians of willing adolescents where written informed consent could not be obtained. The amendment was approved (Appendix 1).

Participants consented both to an interview or focus group as well as the audio-recording of the interviews or focus groups. During the fourth study phase, a clause requiring consent to obtain information from their patient folder such as blood results, their clinic attendance and medication was included. English consent forms were translated into Afrikaans and isiXhosa and the translations were reviewed and compared by professional language editors to ensure the correct educational reading levels and meaning. The researcher, although a professional nurse with experience in working with children and adults with HIV, was not in any way involved in the clinical care of the adolescents at the time of the study and was not known to the adolescents in any way. There was, therefore, no conflict of interest.

The anticipated risk of participating in the study was minimal for the participants. However, during the fourth study phase, three participants became emotionally distressed when completing the questionnaire. Two of these participants were immediately referred to the on-site counsellor and completion of the questionnaire discontinued and the other participant wished to continue and thus completed the questionnaire. None of the participants became distressed during interviews or focus groups in the first and third study phase and there was no need for referral or follow-up counselling and support.

Participants received an R80 reimbursement for participation in interviews or focus groups to compensate for their time and travel costs. Participants who completed questionnaires received a R30 food voucher to compensate for their time and were only reimbursed for travel if they needed to come to the site on a day that was not a usual clinic follow-up. Refreshments were provided during interviews and focus groups.

The researcher did not disclose any confidential information from the participants to the healthcare workers. However, participants were informed at the onset of interviews that should any form of child abuse be identified, the researcher would be legally obligated to report it. This was, however, not necessary. Table 3.7 illustrates how the rights of the participants were protected before, during and after data collection.

Table 3.7 Protection of participant rights (adapted from Richie et al. (2014:83))

Before data collection	During data collection	After data collection
Information about the study provided and why participants were selected to participate. Knowing what to expect and being able to prepare in terms of the topic. Not pressurising participants to take part. Adolescent assent and parental consent. Openness, honesty and being available to correct misunderstandings.	Being able to exercise the right not to answer a question or to say more than they want. Enough time given to think and answer questions. Allowance made for them to add additional topics in the interview or ask questions during or after questionnaire completion. Free of intimidation and judgement. Left without negative feelings about participation.	Right to privacy and anonymity respected in storage, access and reporting. Unbiased and accurate reporting. Feedback provided to certain participants following the qualitative phase. The research has a social benefit since the tool can be used to identify adolescents who need SM support.

Ethical issues during the individual interviews were helping participants to manage the extent of disclosure due to the intimate nature of an interview and ensuring that participants left the interview feeling “well” (Ritchie et al., 2014:86). The participants were assured that they only had to disclose information that they were comfortable to disclose. The researcher assessed the level of comfort or distress of participants during the interviews. All the participants expressed that they enjoyed taking part in the interview. They were, however, encouraged to contact the researcher if they needed to share any additional information. Detailed personal accounts may raise issues about potential identifiability in reporting. The researcher therefore did not include accounts containing specific personal information in the participant quotations. The researcher also had to manage expectations of further interventions and follow-up. The participants enjoyed the sessions and asked whether these sessions would continue. The researcher had to be frank by disclosing that the sessions were for research purposes only.

Ethical issues in the focus groups included the risk of participants not respecting confidentiality and the risk of disagreements between group members leaving some participants feeling uncomfortable. The researcher emphasised confidentiality before, during and after the focus groups and managed the discussion by stating specifically that there were no right or wrong answers. There was no conflict between participants in the focus groups.

3.8.1 Right to self-determination

The right to self-determination supports the ethical principle of respect for people. The researcher showed respect to the participants by making sure undue intrusions were avoided. The researcher planned the research activities carefully and took care not to put a burden on the participants. Care were taken that the data collection timeframes (interviews, focus groups, and questionnaires) were not too long. The research did not include any additional activities for the participants. Adolescents who were involved in the first study phase, were invited to participate in the third phase, but only those who were willing were included. The researcher also tried not be unduly intrusive by not probing very sensitive issues if the participants appeared uncomfortable.

The researcher explained the study and expectations of the participants when recruiting them in their preferred language. Adolescents first indicated whether they wanted to participate and then provided the details of their parent/caregiver if they were not with them and indicated whether they were comfortable with the researcher contacting their caregivers. The researcher ensured that each adolescent understood that they were not obliged to participate (that they had a choice), that the research was not part of their routine care and that even if their parents consented, they could still decide not to participate. They were also informed that they could withdraw from the study at any time if they so wished. Adolescents were assured that their care would not be adversely affected if they did not want to participate. The clinic staff further reinforced the statement that the research was not part of their clinical care. Those caregivers who were not present with the adolescent were telephonically informed about the study in their preferred language. They were provided with an opportunity to ask any questions about the study and they were informed that the care of the adolescent would not be adversely affected if they declined to participate in the study. Undue influence to participate was therefore prevented by providing full information, ensuring comprehension and voluntariness. Structural coercion was prevented by not offering excessive reimbursement (Fisher, 2013:358).

Informed consent was obtained as discussed above and the researcher assessed the participants' understanding and asked if they had additional questions before and after data collection.

3.8.2 Right to confidentiality and anonymity

Confidentiality and anonymity supports the participant's right to privacy of information. Participants used pseudonyms or numbers during the interview or focus group discussions. Where names were mentioned accidentally, it was replaced with a pseudonym in the transcripts. The professional transcriber and study fieldworkers signed a confidentiality

clause. The data was only available to the researcher and study supervisors. As discussed above, focus groups may have particular risk for accidental breaches of confidentiality.

Personal information, for example, consent forms and Excel sheets with participant characteristics were stored separately form questionnaires, interview recordings and transcripts. Paper documents (consent forms and questionnaires) are stored securely in a locked cabinet at the researcher's workplace.

3.8.3 Right to protection from discomfort and harm

The right to be protected from discomfort and harm due to a study supports the ethical principle of beneficence, which states that one should do good and prevent harm. The researcher took care to avoid potential adverse consequences of the data collection process. Participants may feel particularly vulnerable after sharing personal experiences or emotions. The researcher tried to build a rapport with participants by meeting them at least once before conducting the interview or the focus group. It was also explained that they did not have to share any information they were not comfortable with and could leave the interview or group at any time if they so wish.

Accidental HIV disclosure was prevented by asking healthcare workers to identify adolescents who have been disclosed to. In addition, fieldworkers screened for disclosure by asking the adolescent and/or the caregiver if they knew why they were attending the clinic or taking treatment. Those adolescents who were not sure were not included in the study and referred for further counselling. Two adolescents at one of the study sites became emotionally distressed in the beginning of the questionnaire when completing the questions about when they were diagnosed with HIV. They were referred to the on-site counsellor and upon further investigation, it was discovered that they were aware of their status since their caregivers had disclosed to them, but that they had not fully accepted it. This particular clinic did not have a system in place for adolescent HIV care which may also have contributed to this. Although the parents said they had disclosed to the adolescents, they were not known to the on-site counsellor. As previously mentioned, one adolescent became emotional while completing the *Symptoms* section of the questionnaire, but eventually completed the questionnaire. One caregiver informed a fieldworker that one of the participants was emotional after completing the questionnaire. The participants were referred to the counsellor at the study site.

3.9 SUMMARY

In this chapter, a detailed description of the research methods followed in each study phase was provided. The researcher discussed each phase separately in order to clearly convey the methods followed in each step.

In the first study phase the researcher used IP in order to elicit the components of adolescent HIV self-management in a South African context from adolescents, caregivers and healthcare workers through individual interviews and focus groups with 56 participants. Items for inclusion into the Adolescent HIV Self-Management (AdHIVSM) measure was written in phase two using the qualitative data from phase one, the literature, and other measures of self-management yielding an initial list of 55 items. During phase three, items were refined through cognitive interviews with adolescents and caregivers adding an additional 10 items. Sixty-five items were then reviewed by 11 experts to assess content validity and clarity. Based on the feedback, 21 items were removed and some items revised leaving 44 items for pilot testing. The AdHIVSM and other measures were translated using standardised methods and then piloted with 33 adolescents. No changes to the piloted version of the AdHIVSM were made. In phase four, 385 participants completed questionnaires in order to assess the psychometric properties of the developed AdHIVSM. Sixty-three participants completed the AdHIVSM between one and three months after the initial assessment to assess temporal stability.

The following chapters will focus predominantly on the findings of each of the study phases and discuss these in the context of relevant literature.

CHAPTER 4

REALISATION OF ADOLESCENT HIV SELF-MANAGEMENT

4.1 INTRODUCTION

The findings for the first phase of the study is discussed in this chapter. The first phase of the study aimed at exploring the realisation of adolescent HIV self-management from the emic perspectives of adolescents, caregivers and healthcare workers. Within the context of instrument development, the first phase encompassed the development of the construct of interest. Researchers should be aware of their own personal beliefs as it relates to their overall worldview, research philosophy and the discipline-specific philosophy. In this chapter, I incorporate my voice when reporting and reflecting on the study findings. My personal philosophy is pragmatism and is also strongly influenced by my nursing background that involves caring for patients and acknowledgement of the total human being (physical, spiritual, emotional and social). Although I had in-depth knowledge and experience of HIV management, I did not have extensive experience in the management of adolescents living with HIV. I discovered, based on the literature and discussions with colleagues that adolescents seem to be a relative complex group and that complete or "ideal" self-management may not be entirely feasible to them. However, I entered the first phase of the study with the assumption that adolescents are able to make their own decisions regarding their health and that they should be empowered to do so. My social and cultural context were in many ways different from that of the participants and may have influenced how I interpreted participant accounts. Further, my fore-structure and understanding of the components of self-management and my own being in the world may have influenced how I constructed the themes. This was mitigated through declaring my assumptions, triangulating data collection methods, keeping a reflective journal and peer debriefing with the study supervisors.

It is important that the voices of key informants (individuals to whom the instrument will be administered), are heard with the view of understanding their cultural and social milieu and thus the development of an instrument should be contextually sensitive (Onwuegbuzie, 2010:63). This was achieved with a combination of individual interviews and focus groups. Field notes were kept of observations made when visiting study sites and personal reflection on interviews and focus groups which were integrated in the data analysis. An audit trial was kept. A detailed description of the methods followed was provided in chapter 3.

4.2 PARTICIPANT CHARACTERISTICS

In total, 18 individual interviews were conducted across three groups. Six individual interviews were conducted with healthcare workers who were all females - three Coloured and three

Black. Two were doctors, two nurses and two counsellors. The mean age was 44 (range 31 to 58) and their average years of experience working with adolescents was 7 years (range 1 to 12). Two interviews were conducted in Afrikaans, two in English and two in isiXhosa.

Secondly, six caregivers were interviewed individually. All caregivers were female and looked after the adolescents for an average of 15 years and had a mean age of 38 (range 34 to 52). Five of the six participants were mothers of adolescents and one was a grandmother. One caregiver was Coloured and five were Black (although one of the Black caregivers was married to a coloured man and she spoke Afrikaans). Four interviews were conducted in isiXhosa and two in Afrikaans.

Lastly, of the six adolescents interviewed, three were male and three female. The average age was 15 (range 13 to 18). One was Coloured and five were Black. One interview was conducted in Afrikaans, two in English and three in isiXhosa. All the adolescents were virologically suppressed based on their most recent VL.

Five focus groups were conducted with five to nine participants in each group in which 38 adolescents participated. The mean age was 15. Fifteen participants were male (39%) and 23 (61%) were female. Eight (21%) of the adolescents were Coloured and 30 (79%) were Black. All but one adolescent were on ART and one adolescent was on lamivudine (an ARV) monotherapy. Six (16%) had detectable VL (their VLs were not suppressed or were more than 400 copies per ml). All the adolescents reported to be in school. One focus group was conducted in Afrikaans and English; the other four focus groups were conducted in isiXhosa and English.

The group of adolescents who participated were all possibly infected with HIV at birth or at a young age. The assumption was that they were perinatally-infected since most adolescents had been on ART since they were small. Infection could, however, also have occurred through other routes of transmission such as child molestation or rape although only one healthcare worker mentioned this. Based on their narrative accounts, some adolescents were diagnosed late (after the age of 10). This may have been due to factors such as non-disclosure or other routes of transmission.

4.3 FINDINGS

Five main themes were identified in the study. These themes had several sub-themes. Themes and sub-themes are presented in Table 4.1**.**

Table 4.1 Themes and sub-themes

Themes		Sub-themes
4.3.1	Self-management processes and behaviours	Knowing and understanding Believing and valuing Self-regulation Coping Communication and disclosure Social facilitation
4.3.2	Caregiver challenges	Knowledge and skills Socioeconomic difficulties Responsibilities
4.3.3	Putting the spotlight on HIV	Stigma Fears of rejection Telling lies
4.4.4	Healthcare system	Adolescent preferences Clinic or hospital functioning Healthcare worker attitudes
4.4.5	Factors influencing self-management	Disease and treatment characteristics Individual differences Family context Health system structure and functioning Community influences

4.3.1 Theme 1: Self-management processes and behaviours

All the themes that related to how self-management was realised in the context of the participants' lives were grouped into one main theme. This theme encompassed self-management processes and self-management behaviours as described by the participants and interpreted by the researcher to relate to the constructs of self-management. These processes and behaviours formed the sub-themes: knowing and understanding; believing and valuing; self-regulation; coping; communication and disclosure and social facilitation. Each of these sub-themes is discussed.

The interpretive researcher creates a discourse between the lived experiences of participants and practical concerns through engaged reasoning and immersion in the world of the participants (Chan et al., 2010:115). Persons dwell in a world of common meanings, habits and practices that are socially disclosed or encountered. IP is concerned about how a person is orientated meaningfully in their situation and how their life events shape their present experiences (Christ & Tanner, 2003:204). Healthcare workers, caregivers and adolescents living with HIV therefore may share common meanings of adolescent HIV self-management due to frequent interactions and shared "disclosive" spaces (Chan et al., 2010:116).

4.3.1.1 Knowing and understanding

Any management approach to chronic illness commences at diagnosis or when becoming aware of one's illness. This awareness is followed by increased knowledge of the illness. Although knowledge is not the only determinant of self-management behaviours, it can be inferred that without awareness and some knowledge, there can be no self-management. This sub-theme involved what adolescents understood about their illness from the perspectives of the adolescents themselves, the caregivers and the healthcare workers.

A central concern identified from the interviews with healthcare workers and caregivers was that in order for adolescents to participate in their own care and take responsibility, they need to know and understand that they have HIV, why they are taking treatment, what behaviours are healthy for them and why they should keep clinic appointments. The knowledge of being infected with HIV can almost be described as an awareness that does not disturb and hinder. Although adolescents should be aware of their diagnosis, the awareness should empower them to self-manage rather than leave them distressed. One caregiver expressed it as follows:

> *She must understand how she lives, know that she is HIV-positive, that should stay in her mind, I don't mean it should disturb her but she must know that she is not different from other people who have illnesses, she must not think that "maybe I'm going to die tomorrow," but she must care for her health and know that "I'm living like this now*." [Caregiver 5, Mother]

HIV is a sensitive issue for parents to discuss with adolescents and therefore healthcare workers have to provide encouragement and support with the disclosure process and provide information about HIV. The caregivers were uncomfortable to talk openly about the illness and the healthcare workers were frustrated by the caregivers' reluctance to disclose the HIV status to the adolescent. Understanding seems to be a process that is facilitated through repeated conversations and knowledge transfer that would be enhanced if healthcare workers and caregivers share the responsibility. An exemplar identified was that the young adolescents seemed to have very little understanding about how they were infected and how the virus can be transmitted to others. Sometimes caregivers did not disclose to adolescents and they learned about their status from healthcare workers at the clinic or came to their own conclusions.

> *They told me that my mother infected me with HIV, it's like she was helping someone, I don't know what was wrong with this person but she was bleeding, so they are saying the reason they are giving me these pills is because they don't want this virus to increase*. [Female adolescent 5, 14 years]

Yes, like I was nine when I found out. I was like ja, I had it. Like I feel sick, I started losing weight, I'm like what's happening to me. They took me to the hospital. I didn't know that I was HIV-positive. I just found myself taking medication. Then I'm like no, you add one plus one, this medication, why am I taking for such a long time when I'm feeling nice like this. Then I asked my dad what was wrong with me, and he's like quiet, I'm like "what's wrong with me?" They're like you are HIV-positive. Like yoh, that is so sad, and you know, I almost started crying. That's like forever man. [Male adolescent, Focus group 1]

Caregivers were mostly reluctant to talk to the adolescents about HIV because they lacked knowledge, felt uncomfortable or did not know what the right age to disclose was. Some felt that their adolescents must utilise other sources of information such as reading books. Other caregivers felt more comfortable since they were also living with HIV, but expressed that it requires a lot of time and effort. One mother who was an HIV counsellor commented:

She asked many questions about HIV, but must I eat with them, may I sit with them mommy, and they're saying you mustn't touch someone with that and so on. So I had to sit and teach her. It took time for her to understand it. [Caregiver 3, Mother]

Healthcare workers felt that even if adolescents had suspicions that they were HIV-infected or knew their status, some were still not ready to accept it. In some cases, adolescents knew that they had HIV, but their understanding of the long term implications of living with HIV were still limited.

They still have a lot of anger issues or they are still in denial and do not really understand what is going on. [Healthcare worker 1]

Like some kids are a lot more mature, and have a better understanding, where other kids, their thinking is still very concrete and they can't think further than like next week. [Healthcare worker 3]

Another central concern mentioned by healthcare workers was that the mother or the adolescent may deny the fact that they are HIV-positive which could lead to non-adherence or exploring alternative therapies resulting in the possibility of pain and tragedy. This illustrates that adolescent self-management processes do not occur individually, but that it is a shared process that occurs within the family and can influence self-management behaviours such as treatment adherence in a positive or negative manner. The caregiver's past experiences in dealing with an HIV diagnosis may influence their behaviours and actions, which in turn is observed by the adolescent and is likely to influence the adolescent's behaviours.

> *Firstly, they need to know that HIV is not curable, secondly, they need not to listen to the people who says HIV is curable. There is a child who was in club 2, he got infected from his mother, so what happened to his mother was that she was going to the gospel church, so she didn't use the ARV's, she just started them now recently, so she stopped him from using the treatment, he failed the second line I mean he started second line, he failed in second line as well and started third line, and the mother also started treatment, so what happened is that he passed away. Oh before he died he hit his mother because she didn't want to accept the status.* [Healthcare worker 4]

Central to being adherent to their treatment is understanding why they have to take treatment. This was mentioned by adolescents, caregivers and healthcare workers. Knowing how HIV is treated and managed is an extension of the knowledge that they are infected with HIV and their understanding of HIV. Many adolescents verbalised that the main reason why they were non-adherent to treatment at some stage was that they did not understand why they were taking treatment. While some adolescents knew their medications, others were unsure. Many of them were on ART since they were small and their treatment had changed over the years. This could have been due to dose increases or a change from solutions to tablets or changing to a fixed-dose-combination tablet when it was appropriate for their weight and age. These changes, however, may cause adolescents to become confused about their regimen or their tablets.

> *I don't know mine because they always change them every year.* [Female adolescent, Focus group 3]

This is an example of how past experiences may influence current behaviours. Adolescents and even caregivers may see the doctor or nurse as being in control of the treatment and therefore do not think that it is important to know their treatment. They see healthcare workers as the holders of knowledge and do not feel the need to acquire knowledge themselves. Other adolescents said that it is important to know their treatment, illustrating a sense of responsibility.

> *I think that is important because you can make a mistake if you don't know your pills, you can be given the wrong tablets and use wrong tablets then you become sick.* [Female adolescent, Focus group 3]

It is evident that adolescents make decisions about taking or not taking treatment based on their knowledge and understanding of why they are taking treatment and an assessment of their own physical health. Since many of them cannot remember being ill and currently feel healthy, they do not see the need for treatment. Some would stop their treatment because they did not understand the need for taking it.

> *I didn't find it necessary. Like I pay soccer, I eat properly and why should I take it? I'm healthy. I don't find the reason for it*. [Female adolescent, Focus group 1]

Healthcare workers strongly felt that adolescents have to understand why it is important to take their treatment on time as well as the consequences of not taking their treatment. Some felt that adolescents need to have a basic understanding of what a CD4 count is (their immune status) and their VL (virus count in the blood stream) and how not taking their treatment will affect these measures. Other healthcare workers were more sceptical about the ability of adolescents to know their biomarkers (CD4 count and VL) and did not seem to discuss these with the adolescents.

> *So I always tell them, you must know your last CD4 count, and then when we take the blood, with the next visit you must know how was the other previous so that we can discuss why is that low, why is that high now, and all that.* [Healthcare worker 6]

While some adolescents had an idea of what a CD4 count and VL is and should be, most were not sure. An exemplar identified was that adolescents knew that the healthcare workers can see from their blood results whether they are taking their treatment or not and expected the doctor or nurse to tell them if they were doing well on treatment or not, rather than knowing their CD4 count and VL themselves. One healthcare worker reported that the caregivers would report that the adolescents only take their treatment very well the week before they have to come to the clinic or hospital. It was clear that some adolescents merely took the treatment because the caregivers and doctors thought it was important. They were not yet at a point where it was something that was important to them. This could be in part due to taking treatment since they were young and accepting that it was not something they can control.

Understanding and realising why they are taking treatment goes hand in hand with taking responsibility for their treatment and learning how to manage and integrate taking treatment into their daily routines. There should be an understanding of when treatment should be taken and what should be done if a dose is missed. Sometimes there was confusion about whether treatment can be taken with or without food. Both the adolescent and caregiver should have this knowledge since there is a separation from the caregiver that starts during adolescence.

> *They must know, because if they do not know… look, if they are young their mothers give them the tablets and then a teenager later has friends and friends from outside*. [Healthcare worker 2]

Healthcare workers mentioned that adolescents seemed to have very little knowledge about risk behaviour. Education about sexual behaviours and the use of drugs and alcohol is very important since most adolescents begin experimenting and are exposed to these behaviours

in their communities. Some adolescents are involved in sexual relationships and knowledge of protecting themselves and preventing transmission is important. Sometimes there can also be misconceptions or myths about certain sexual behaviours that need to be addressed.

> *When some of them ask you when it is safe to have a baby, I mean. There are children who get pregnant. These are the things, and as you heard one guy spoke about his sexuality and said that God gave him that thing for his own pleasure and he refuses to use a condom… This is what he said, what if the girl fell pregnant, he said, "then I am gonna feed her steel wool, I am gonna put steel wool in her tea or coffee."* [Healthcare worker 2]

Adolescents did not mention knowledge of HIV and sexual risk behaviours as a very important part of living with HIV. Yet, some of the older adolescents were aware of the risks.

> *When you are having sex you need not to spread that thing, you have to use a condom.* [Male adolescent 4, 16 years]

> *You should not just do anything like drinking alcohol, having unprotected sex because you can get pregnant and not reach your goals.* [Female adolescent 6, 18 years].

Some adolescents were also very aware of the fact that they can transmit HIV to their friends through blood contact.

> *But for me it's actually like if I bleed, it's like most of my friends, my friends that I hang out with at school, they know, and my best friend at home, she knows, so people that I hang out with, they will be like are you okay, and if I bleed, I don't want anyone near me, that's it.* [Female adolescent, Focus group 1]

A central concern of healthcare workers was that schools are not a reliable source of information. A healthcare worker explains what happened when they disclosed an adolescent's HIV status to him:

> *They have a little bit of HIV education, and I find what they tell the kids is incorrect because there is a boy who was diagnosed, but he was like 12 or 13 already, and so when I disclosed to him he started crying. So I asked him "why are you crying?" So he said he learnt at school that people with HIV die, and he doesn't want to die.* [Healthcare worker 3]

Participants did not emphasise knowledge of transfer to adult care as an important component of self-management. In the hospital setting adolescents were being prepared for transfer to adult care, but there seemed to be no plan or preparation for transfer in place in the community clinic setting. Since the adolescents are used to the individualised approach to care in the paediatric setting they may struggle to adapt in the adult setting.

Then like I said, it's also the transition between the paediatrics and the adolescents, and we find a lot of them, once we transfer them out, they actually default for a while, because like you said, when they go to the adults it's not the same, and they are not treated with respect, or they are forced to have to wait. They also want people to take an interest in them and they don't want to be a statistic, like just a number. Like here's your medicine, go. [Healthcare worker 3]

There was a shared understanding amongst participants that knowledge and understanding about one's HIV status; what HIV is; why one needs to take treatment; what constitutes healthy behaviours and how the healthcare system works are important components of living with HIV. It forms an important platform for adolescent HIV self-management and should be continuously enforced. One adolescent girl mentioned that the healthcare workers do not have the knowledge of living with HIV on a day-to-day basis. This illustrates the dichotomy between knowledge of the medical management and knowledge of living with HIV (dealing with emotional and social consequences).

4.3.1.2 Believing and valuing

This sub-theme involves the beliefs and values adolescents, caregivers and healthcare workers have about HIV. These beliefs and values are likely to influence self-management behaviours. Since most of the adolescents had no symptoms of being ill or any memories of being diagnosed, a pattern identified was that they expressed doubt about whether they are HIV-positive at all or were unsure.

Some, they are doubtful, they are having the treatment, but they are doubtful whether they are HIV-positive. [Healthcare worker 6]

Then at the bottom now, my status is. Some know, some they don't. Some, they just leave it blank, and then you see now, it's not okay on the face, the expression. Then you find out there is something. After you collect these little papers, then you ask them, why did you, then you pick up that. [Healthcare worker 6] [This healthcare worker explained an activity she does with the adolescents in the support group to ascertain if they are aware of their HIV status. She handed a paper to them asking some personal information followed by a section asking if they know their HIV status].

The process of acceptance is intertwined with what the adolescents believe about themselves and their identity formation. It seems as if HIV becomes a part of the adolescent's identity and it makes them feel different from their peers. It may affect their ability to form their own identity and may cause role confusion that may take longer than normal to resolve. This process of acceptance does however seem to get better for some adolescents as they grow older. Yet, some may remain uncomfortable for longer.

So nowadays when I take my medication, I don't see myself as different. I am just an individual. Yes, I have to like take these pills, but nothing about me changes. It doesn't change my name, my fingerprints, you know, I'm still the same when I look in the mirror and stuff like that. [Male adolescent, Focus group 1]

I noticed that she had a sad face, when we were at the club she once said she hates to be reminded of taking her pills, even if she was about to take them, once someone reminds her to take them, she just stops taking them, because she is fed up its not her fault that she is HIV-positive, it's because of this person. [Healthcare worker 4]

It was strongly emphasised by healthcare workers and caregivers during the interviews that it is important for adolescents to believe that they have a future that can be normal. Certain healthcare workers expressed that some adolescents thought that they would not live very long and were scared of dying. Other healthcare workers reported that adolescents had many dreams for the future such as having children, getting an education and having an occupation. Healthcare workers frequently talked about how they motivated the adolescents by telling them that they can accomplish just as much as people who live without HIV. A belief that there is a future may influence adolescents' motivation towards taking treatment and attending school. Caregivers and healthcare workers explained to adolescents that they can live a normal life and have a future.

I talk to him I say [child's name], don't count yourself as a child who is already dead, I also don't count myself as dead because I am living with HIV and you as you are living with HIV, we are the ones who are going to live longer than those living with diabetes. [Caregiver 2, Mother]

An HIV-positive person can do what an HIV-negative person does, but it depends on what a person wants. [Healthcare worker 5]

An exemplar was that the beliefs and attitude of caregivers, the family and healthcare workers, as communicated through their actions and words, influences the beliefs of the adolescent about the disease and how they see themselves. More than one adolescent mentioned how they looked up to their mothers as examples or role models. Healthcare workers reported that the attitude of the caregiver influences the adolescent's attitude, especially the young adolescents.

But I find if the parents' attitude towards HIV and treatment is positive, it tends to be better for the kids, because the kids tend to be more positive. But if it's something that the parent hides away and is negative and hasn't accepted properly, then the kids will tend to feel similar about it. [Healthcare worker 3]

The sense of wanting to be normal goes hand in hand with the adolescent's desire not to be different. It is difficult for them to accept that they have an illness and have to take treatment which their friends do not have to do. What exacerbates their feelings is that most of them, since they were perinatally-infected, did not have any choice since they were born with HIV. This evidently leads to questions such as 'Why me?' and in some cases blame and anger. The perinatally-infected adolescents therefore feel that the fact that they have HIV was out of their control, yet they are expected to deal with the consequences.

> *I do understand but I always have questions when I'm alone, "why me God" I don't blame God, don't make me like that mean childlike* [Sic]. *I always like ask why me, why shouldn't be anyone* [Sic] *that has this kind of sickness that I have. But in reality I agree that I do have it and it will last forever and ever, until I die.* [Female adolescent, Focus group 2]

> *'Sometimes you feel angry because it's not what you like, it's not what you choose*. [Male adolescent, Focus group 5]

Most of the time what makes adolescents who live with HIV feel different is the fact that they have to take treatment.

> *But the thing is, you feel perfectly normal during the day, and then seven o'clock strikes and you're like okay, I'm different. So you don't drink it because you want to go on living life like a normal person*. [Female adolescent, Focus group 1]

A central concern was the need to be seen as and feel normal. I personally remember that I told one adolescent girl that I want to know more about how living with HIV is like and she said to me that it is '*just normal*'. Having a normal life needs to be unpacked, for example, what it means in terms of current behaviours and future relationships. The whole idea of normalcy or of what constitutes normal behaviour may be context- and time-specific. Even though adolescents may initially feel different because they have to take treatment, their perspective may change as they grow older and realise that taking treatment is only one aspect of their lives. Certain behaviours such as attending the clinic regularly and taking treatment may be seen as normal for adolescents since they have been doing it for a long time. It may be easier to normalise these medical management activities than dealing with HIV stigma or engaging in romantic relationships. One healthcare worker explained her idea of normalcy:

> *Like coming to the hospital every month is not normal, but for them it's normal. They like it, it's weird (laughs)… I always tell them having HIV and taking your meds is like brushing your teeth (chuckles). So it's something that takes a few minutes twice a day, but if you don't do it, you'll end up with rotten teeth. The same story with your meds, it takes like two minutes in the morning, two minutes at night, but if you don't do it you're going to land up*

> *being sick. Just to put it into perspective, like two minutes out of like 24 hours is not a big thing, and there are more important things in life than HIV, because you have to grow up, you have to interact with other people, you have to study, you have to learn, you have to have direction and focus to get where you need to get.* [Healthcare worker 3]

Beliefs about treatment are also very important. Adolescents need to believe that the treatment will help them, but that it will not cure them. Some participants believed that if you take your treatment, people will not notice that you are HIV-positive since the treatment will conceal the signs and symptoms of HIV. This provided motivation for adherence. A repeated assertion was that although adolescents believed that taking treatment would keep them healthy, they did not feel that they wanted to take treatment for the rest of their lives and had hopes for a cure or that the human race will evolve to overcome HIV. This indicates that their beliefs are also influenced by what they learn in school or by other sources.

> *I can think that but I do believe that maybe in the next few years there will be a cure for HIV, because now I can see things are improving*. [Male adolescent, Focus group 5]

> [L]*ike they say that in order for anything to survive, you either have to adapt or die… So I think that maybe the human race will adapt to the virus, but I'm not sure.* [Female adolescent, Focus group 1]

An interesting finding was that some parents tried to warn their adolescents about the dangers of drugs by saying that ARVs are drugs as well.

> *So I think if we could sit and explain to the child, for example 3TC contains a bit of tik. So if you take 3TC in the morning, and then you go and smoke drugs, you are killing yourself because you have overdosed the 3TC in your body, it will not work properly*. [Caregiver 2, mother]

Some of the adolescents referred to themselves as '*drug addicts*'. Yet others had a different view.

> *Taking your ARVs, it's not like other drugs like alcohol, dagga. It doesn't need to be like when you smoke dagga or drink alcohol. When you drink alcohol, you will be like in another motion. When you drink ARVs, ARVs do not go to your mind*. [Male adolescent, Focus group 5]

In the community context, spirituality and faith seemed to play a significant role in people's lives. The dominant spiritual beliefs were Christianity and believing in ancestors through making use of sangoma's (traditional healers). There were varied perspectives on the role of spirituality in their personal lives. Although many adolescents seemed to be involved in

religious activities, they did not seem to have internalised beliefs from caregivers and were still trying to ascertain their own beliefs.

> *Yes, I also do believe in God, because I'm a Christian. It's the thing that my family actually do. Like we believe in God, so I grew up with my family, they believe in God, so I have to believe and I like it*. [Male adolescent, Focus group 5]

> *I'm still stuck because ever since I heard that a certain pastor was feeding people with worms*. [Female adolescent, Focus group 3].

A number of caregivers had very strong beliefs in God and expressed faith for complete healing, especially if they had gone through difficult times in raising the child or if the child was very ill at birth. More than one adolescent reported that they have been prayed for in the church for healing. In some ways, this provided hope for being cured and in other ways the adolescents were very disappointed, some even distraught, that they were not cured.

> *Then she's like you need to come with me, Friday to church, we have like a service and they heal you.* [Female adolescent, Focus group 1]

> *The following day I was going here I still have it, but I don't know but I cried, because like I believed her, seriously, seriously, seriously and I cried.* [Female adolescent, Focus group 2]

Most healthcare workers did not express that spirituality was something important to adolescents and it did not appear to be something that they talked to the adolescents about. One healthcare worker had an open approach to spirituality.

> *So that thing hurts that one, then they come and tell me and I say no, we are all from God. God can't let us suffer and doesn't give us a solution. Look now, we've got the ARVs*. [Healthcare worker 6]

The dichotomy of listening to medical advice (taking treatment) and believing that HIV can be cured in some supernatural way may also create stress within the adolescents and disconnectedness from family (who believes in the spiritual) and healthcare workers (who may insist that taking medication is the only way to treat HIV and that spiritual beliefs may lead to non-adherence).

Beliefs about having a future that can be normal is therefore important to foster self-management. The beliefs and values of adolescents are strongly influenced by their caregivers and healthcare workers, but also by their own experiences, information in the media and society in general.

4.3.1.3 Self-regulation

The sub-theme of self-regulation encompasses all the processes (for example, making decisions and setting goals) adolescents engage in to manage their chronic illness. This is either done individually or in collaboration with caregivers, peers and healthcare workers. Self-regulation usually involves processes such as planning, goal-setting, self-monitoring, reflective thinking and self-evaluation. Self-regulation processes may be challenging for adolescents since they are still developing many of the cognitive skills required to think abstractly. Healthcare workers seemed to be sceptical about adolescents' abilities to self-manage.

> *I have little hope for self-management since adolescents only think about the moment, they only think about keeping themselves happy.* [Healthcare worker 1]

As other adolescents, they did not always anticipate the consequences of their actions and tended to live in the here and now. One example was that adolescent boys in one of the focus groups reported having sex without condoms without anticipating the consequences such as HIV transmission or pregnancy. When I asked them 'What if these girls become pregnant?' they said that they are not ready to be fathers since they are still children themselves. However, adolescents did demonstrate some level of independence regarding certain self-management processes such as planning and self-evaluation. This included integrating aspects of their chronic illness into their daily routines and lives. Others were also aware that their actions have consequences.

> *I need to have my own time table, have time for everything, and have time for my pills and time for taking care of other things*. [Male adolescent 4, 16 years].

> *You should first think about its consequences before you do it*. [Female adolescent, 18 years].

As mentioned by adolescents, caregivers and healthcare workers, one of their daily tasks is to take treatment . This is done either once or twice daily depending on the regimen they are on and requires self-monitoring. Many adolescents claimed to do this on their own and to remember without being reminded while some adolescents still needed to be reminded by their parents to take treatment.

> *Nobody reminds me, I'm used to it, because seven o'clock I know it's my time to drink pills.* [Male adolescent, Focus group 5].

> *Even though they know that the time for the pills have passed, but they want to be reminded, for them to go to the room and take their pills the mother should say it, once the*

mother says no so and so why didn't you, then they will say "you were not here you didn't remind me." [Healthcare worker 5]

Caregivers explained that they are trying to teach their adolescents to take responsibility for taking the treatment on their own. In certain cases, adolescents used pill-boxes to remind them to take their treatment. Others used their phones or they connected the time they had to take it to a television programme broadcasted every day. Some did not use any reminders and healthcare workers and caregivers mentioned that giving cell phones to them did not help since they were either stolen, lost or sold. Pill-boxes seemed to be a good way of teaching the adolescent to take responsibility of taking their own treatment and this was done from the age of eight or nine.

She must teach the child to use the pillbox. You fill up the box, it is for a week, Monday to Sunday, morning and evening. Teach your child to use the pill box. [Healthcare worker 2]

A central concern in the narratives of healthcare workers and caregivers was that taking treatment is generally not prioritised above other activities and that normal adolescent activities interfere with adherence. A pattern identified was that although adolescents were aware that they need to take their treatment, forgetting was common. This was especially evident when taking treatment interrupts other activities such as playing outside with friends. Forgetfulness may be partly due to their cognitive capacity, but more probably because taking treatment is not a priority in the lives of adolescents.

It is not a specific brain problem, they have a problem with forgetfulness this group, but it is also that they are busy with other things, they do not understand that ARVs is a priority. [Healthcare worker 1]

According to healthcare workers and caregivers, young adolescents or pre-adolescents had fewer problems with taking treatment since most of them were still very protected and bound by family routines. As adolescents grow older, they are less bound by family routines and do not come home at the usual time. This presents a potential problem since taking treatment is easier if it can be linked to a specific daily routine. Some adolescents took their treatment with them when going out, but it presented a problem since most of them had not disclosed their status to their friends. One caregiver explained:

Even if he is going to have fun, he must put them in his pocket so that when the time comes, he will set his alarm on his phone, if he chose 17h00, at 17h00 he goes to the toilet, take his medication and come back and have fun with his friends. [Caregiver 2, Mother]

Self-monitoring is more difficult if the treatment regimen is complex. Adolescents who had to take treatment in the mornings and in the evenings especially had a problem with taking the treatment in the morning. When they are late or in a hurry for school, they do not have time to take the treatment. On weekends, due to waking up later than usual, they frequently missed the morning dose or needed to be reminded to take it.

> *No I drink it by myself and then on the weekend my aunt reminds me.* [Female adolescent, Focus group 3]

Another concern was that certain adolescents go through a stage where they refuse to take their treatment or pretend to take treatment and then either throw it away or hide it. It implies that they make very deliberate decisions about not taking treatment that can be due to various reasons. For most, this seems to start at the beginning of adolescence around the age of 11 or 12 and settles later, but for some adolescents it can take months before they are 'back on track'. Some interrupted their treatment for more than a year.

> *I stopped for a year or so, then I started drinking it, but now I'm fine with it*. [Male adolescent, Focus group 1]

Although certain adolescents knew that they should take treatment, and even wanted to, there was goal incongruence or conflicting priorities between taking the treatment and being socially accepted. This goal incongruence therefore leads them to choose what is most important to them. What is most important is usually to be normal and to do the things normal adolescents do rather than taking treatment. More than one adolescent said that they did not take their treatment when going out to a party. Usually this was the older adolescent who wanted to stay out late with friends. Reasons for this differed. Some said that they simply forgot to take treatment with them and did not want to go back home to fetch it, whereas others deliberately decided not to take the treatment because the treatment makes them fall asleep quickly so they are reluctant to take it when they go out.

> *I said I'm not going to worry now, and they were drinking and so on, I was just talking the whole time there. It was for four days I didn't drink my tablets. I decided I'm not going to worry about it.* [Female adolescent, Focus group 1]

It seemed that this stage of rebellion may be connected to adolescents not understanding why they are taking the treatment and questioning why they are not getting better (healed of the illness), why they take treatment if they are not sick or why their friends do not have to take treatment. Others simply become tired of taking treatment every day. Noticeably, many of the adolescents were the only HIV-positive child in the family. They had brothers or sisters who were HIV-negative (due to the mother commencing ART and thus preventing HIV

transmission in subsequent pregnancies), exacerbating feelings of 'unfairness' since many times the younger HIV-negative children received more attention from the caregivers. During this stage of rebellion caregivers are required to directly observe them taking and swallowing their treatment. One adolescent confessed that he used to vomit his tablets after swallowing them, others would spit the treatment back into the glass that they used to drink water from or hide them under the tongue. Healthcare workers advised that parents continue to supervise treatment, even if the adolescents grow older and not impart complete responsibility for the treatment to the adolescent.

> *It is so bad, the supervision must be in such a way that they see how they swallow the tablet, they must check the mouth, because they keep it in their mouth and then they spit it out*. [Healthcare worker 1]

Although self-monitoring of treatment seemed to be the most important self-management component for adolescents living with HIV, not all adolescents were on treatment. One of the adolescents was not yet on treatment even though she attended the support group for adolescents on treatment. I only realised this when the questions about treatment were posed to the focus group. Prior to the latest HIV guidelines, adolescents did not require ART if their CD4 counts were still high. This was, however, not explained clearly to the adolescent since she was not sure why she was not on treatment. She felt very anxious since the other adolescents in the group said that if one does not take your treatment you will die. She commented:

> *Sometimes I feel scared… when I'm sick I think I'm going to die*. [Female adolescent, Focus group 3]

Another task related to the medical management of their illness is attending clinic appointments and knowing when their next clinic appointment is. Older adolescents and adolescents in the community setting tended to attend appointments alone; whereas young adolescents and those attending a tertiary setting tended to be accompanied by their caregivers. Sometimes this was not related to their level of independence, but a practical arrangement since the pharmacy did not dispense medication to children under the age of 14 or for their own safety since it was not safe to travel alone. In some cases treatment was changed particularly in the young adolescents and caregivers felt that they needed to accompany the adolescent so that they were aware of the changes.

> *He was often being switched from syrup to pills, each syrup would be switched to pills as his age increases till now that he is 14. I have been going with him, being the one next to him.* [Caregiver 2, mother]

There were differences observed between the tertiary hospital and the community clinic regarding whether the adolescents came with or without their caregivers. In the community clinic, even the young adolescents came alone. This seemed to be related to the fact that adolescents were seen in the afternoon and they attended an adolescent group. Caregivers who used to come with the adolescent realised that they do not have to come with them anymore since they attend the group. Caregivers also had to take time off from work to attend the clinic and for some that was the reason why they did not accompany their adolescent. One of the healthcare workers explained that it was sometimes difficult to get the parents to come with the adolescent when their attendance was required, for example, for the initiation of ART:

> *Last week still, so the child came alone. The child said when he came, my parents said the doctor can go ahead, but we can't on a 12 year old*. [Healthcare worker 6]

Maturity seems to play a role in whether adolescents attend healthcare appointments on their own, but other context-specific factors may also influence whether they attend alone or with a caregiver. Some adolescents remembered on their own when to attend the clinic; others said that their caregiver reminded them or they came when their tablets were finished. It seemed that if they enjoyed attending the clinic, they remembered more easily to attend. Sometimes the adolescents did not come on their exact clinic appointment dates or times, but they eventually did attend.

> *They look like people who care, because they do come on their dates to the clinic, they do come shame I don't want to lie they come even if they come late but they end up coming*. [Healthcare worker 5]

As illustrated in the above discussion, the participants placed a lot of emphasis on the medical management of HIV. Social and emotional aspects of self-management were less often discussed. The most talked about point that relates to social and emotional management was disclosure. Although most adolescents did not disclose their HIV status, some adolescents made decisions regarding whom to disclose to and talked about how they assessed whether they could disclose their status to a person. They mentioned that one should not disclose to any friend and that one should choose the friends to which you disclose very carefully.

> *Sometimes I have 2 or 3 girls and see their personalities, what kind of people they are, and start a topic by asking them "what would you do if I could have this thing", one will say "no I would continue dating you because it is not the end of life you'll just need to take care of yourself," others would say "no I would dump you" then you can see that this one good than that one, but that one is more valuable than that one, you can see.* [Male adolescent 4, 16 years]

I tried to trick her like if she was positive how she would tell me, and then she told me and then it's when I told her. [Male adolescent, Focus group 4]

Other social aspects of self-management that the healthcare workers emphasised were sexuality, high risk behaviours and choosing the right friends. Adolescents seemed to be aware that they should stay away from friends who are a bad influence and drugs, yet healthcare workers and caregivers reported that adolescents became involved with drugs and sexual relationships at a young age. Healthcare workers realised that it is sometimes not feasible to tell adolescents to abstain from alcohol, sex or partying so they advised them to keep within limits.

Like we had one boy at school, he was a 13 year old boy who used to hang out with a group of boys, and then he said they used to go to a shebeen, get drunk and go to someone's house when the parents weren't there and have sex with each other. [Healthcare worker 3]

I told him the other time, I can tell you to leave the alcohol, but I am not there with you. But at least stop early so that you can still make space to take your tablet. Then he also responds. We talk to them about when to start and when to stop. [Healthcare worker 2]

Adolescents made decisions about using condoms in sexual relationships. Although some were aware that they had to use condoms, it was not always easy to negotiate condom use and many times they did not use them. One boy explained how he does not use a condom when it is not available since he relied on the knowledge that his VL was suppressed. Others justified not using a condom when they were in a steady relationship.

Because I trust my viral load, so if I don't have a condom right now, I have to get going… when it's low, then I can do anything at any time, but about who I am with. If I don't trust the girl, I will use a condom. [Male adolescent, Focus group 5]

When you have been with her once, you can be like skin to skin. [Male adolescent, Focus group 5]

One healthcare worker reported that some adolescent girls would leave their home and live with their boyfriends. Since in most cases the boyfriend did not know about their HIV status, they did not attend their clinic appointments and defaulted their treatment. Yet some seemed to demonstrate the ability not to give in to pressure. Healthcare workers also reported that some adolescent girls asked for contraceptives when they started to be sexually active.

And they tell themselves if the boyfriend is pressurizing her to do something, I know my health status, so we better call it off. [Healthcare worker 5]

Managing emotions seemed to be difficult for adolescents since they have to manage both the feelings of going through puberty and the additional emotional onslaught of dealing with HIV. Adolescents were very sensitive to hearing negative conversations about HIV which could leave them feeling sad or angry. Some also explained how they got emotional when their parents addressed their non-adherence.

> *They are teary, because at school somebody will talk about HIV, meantime he knows of it, he knows he is HIV, but he doesn't want to hear the name of HIV*. [Healthcare worker 6]

> *Anger yoh! I'm trying to manage it, like breathe in and out every time I am angry, it calms the anger down or ignore that thing*. [Male adolescent 4, 16 years].

> *Like sometimes when they see I'm not taking my meds, they sit you down, have that long talk (laughs). I hate those talks man. You just end up crying*. [Male adolescent, Focus group 1]

Goals seemed to be limited to general goals such as being independent or educational and career goals. Very few adolescents expressed goals specific to their health or their disease. Only two adolescents mentioned that they would like their CD4 count to be 1000.

Adolescents therefore demonstrated behaviours such as taking treatment, attending appointments, disclosure and managing risk behaviours at various levels of independence. Self-regulation skills such as planning, self-monitoring and self-evaluation seemed to be limited, but may be due to the fact that these skills are not taught/focused on in either the family or healthcare settings. It further seemed that there were several personal and contextual factors that influenced an adolescents' ability to self-regulate their behaviour.

4.3.1.4 Coping

Coping concerns how adolescents handle and adapt to their chronic illness, difficult situations and circumstances and may also be closely related to or considered part of self-regulation. It concerns their thoughts and actions in dealing with stressful life issues and is discussed here as a separate theme. It appeared to me that adolescents mostly used passive emotion-focused coping strategies compared to actively trying to address the problem or stressor. This may be because stressors such as stigma is not something that they can control.

One of the most difficult life issues to cope with is HIV stigma. Since most adolescents did not disclose their status at school or to their friends and it was not pleasant when other people (outside their family or the healthcare context) talked about HIV. Healthcare workers reported that some adolescents had adherence problems following disclosure that was not well received by their friends. It seemed to be easier for adolescents to cope if they had more knowledge or if they had accepted their HIV status. Healthcare workers and caregivers

specifically emphasised acceptance of their status as key to coping with the illness. Some adolescents had accepted their status and others were still in the process of acceptance.

> *There is time when we accept it, and there are times when you feel like "eish it's hard" and you think like how to accept it, and you feel like lost now, there is no one who could say "am I really like HIV-positive", it's like hard to accept*. [Female adolescent, Focus group 2]

Social support seems to influence how adolescents cope. Coping is easier for adolescents if caregivers have an open relationship with them and if there are other family members also living with HIV. However, few adolescents seemed to seek out their caregivers' support due to the lack of communication about HIV. Siblings or peers in the group helped adolescents to accept their status, how to deal with painful emotions and gave them advice on how to cope.

> *I find kids adapt more if it's something that's open in the house, and the parents talk openly with their kids about it. I find the parents and the kids, their relationship tends to be better, like those kids that I have seen, and their acceptance of it is also better. They accept it earlier. They are okay with it earlier than some of the other kids*. [Healthcare worker 3].

> *It like helps you to be yourself, like this group, because when you're outside, you know, it's awkward for me, you know like in life science when they tell you about infectious diseases. Like HIV and AIDS, I'm like ohhh (laughter). I'm like I know everything about this, you know what I'm saying?* [Male adolescent, Focus group 1]

An exemplar identified was that adolescents actively tried to avoid the stress of stigma by not attending the clinics in their local area or by lying about their illness. One adolescent mentioned that he stopped going to the support group when his friends asked him what he was doing there. It takes time to accept and develop the skills to cope with stigma. A repeated assertion from adolescents was that the way they deal with stigma was by ignoring what other people say. A few mentioned that they will challenge the incorrect assumptions of people or even resort to physical violence. Others tried to motivate themselves emotionally or cognitively through positive thinking.

> *Like to be sure of yourself and be where you are, and not care too much, because as I have said there will always be people talking positive and negative things, so you don't have to care too much because you will end up being in trouble, you need to take care of yourself.* [Male adolescent, 16 years]

> *So, my advice would be love yourself, because I believe if you love yourself as an individual, and you don't put a limit on yourself, then everything else becomes easier*. [Male adolescent, Focus group 1]

It was especially difficult for adolescents when their HIV status was first disclosed to them. Some initially blamed their caregiver and were angry. Several adolescents reported to have had thoughts of committing suicide or trying to commit suicide when they discovered that they were HIV-positive. Some explained that they used drugs or alcohol to cope with the news as an escaping strategy.

> *I remember the time I first heard that I was HIV, I tried to smoke dagga, but that didn't change my way of I would find out I am HIV* [Sic] [He refers to how he used dagga as an escaping strategy after his status was disclosed to him, but realised that it was not the best way to deal with his diagnosis]. [Male adolescent, Focus group 5]

Adolescents tended to manage their stress or coped using distraction such as listening to music or doing sports, since this helped them to feel normal and took the focus off their illness. Others used passive emotional regulation such as meditation or relied on their spirituality.

> *You don't like think about I have HIV and stuff, and then you don't, like when you play, you just don't feel that thing, that pain that you have HIV*. [Male adolescent 2, 14 years]

> *I also used to draw, in my silent moments. I also like yoga*. [Male adolescent, Focus group 5]

> *Some children joke about it (sighs)* [referring to HIV stigma in general]. *But God helps me.* [Male adolescent 1, 14 years]

Medication or adherence related stress was mostly managed through resigning to their fate.

> *I can say I am using it now, I have no choice, you see? But the first time I was taking it, I didn't like it, but now I have no choice, I have to drink it.* [Male adolescent, Focus group 5]

Adolescents also had to cope with bullying which seemed to be common in the schools. This was mostly not related to their HIV status, but to other more general adolescent issues and was either physical or verbal. They were afraid of being teased about their HIV status if their peers found out. One adolescent mentioned that he would join his friends in teasing others so that they would not suspect that he is HIV-positive. Some adolescents looked for support from their caregivers in order to manage bullying.

> *So once she came home and said that the children said she is ugly. Then I understood why. Then I told her, if they ever say to you, you're ugly, you tell them, I am looking after myself, they must look after themselves. And that was her point (laughing). Since that day, when she came back she said, "mommy, the kids said again to me I look ugly, and then I*

told her, I am looking after myself, you have to look after yourself because I think you have a problem with yourself". [Caregiver 3, Mother]

Adolescents have to learn to handle HIV stigma, but it is not easy for them because they are at a fragile stage where their identities are still forming. Coping seems to be facilitated by family and peer support.

4.3.1.5 Communication and disclosure

Communication involves verbal and non-verbal interactions between adolescents, their caregivers, family, friends, peers and healthcare workers. In this context it refers to the types of communication that are necessary in order to facilitate or enable self-management. Adolescents reported that they communicated with caregivers, but in most cases, the relationship between caregiver and adolescent was not characterised by open communication. Talking about HIV was an uncomfortable topic for both adolescents and caregivers and they therefore tended to avoid it. One healthcare worker explained:

These parents do not talk to these children, and these children do not talk to their mothers, she says we last speak here at the clinic and it ends there, we just keep quiet as if nothing has happened. [Healthcare worker 4]

The relationship is especially strained when a caregiver had lied to the adolescent about what was wrong with him/her. One mother explains:

I was scared to tell [child's name] that I was positive, I use to lie to her and tell her that she was using TB treatment, so I asked one of the counsellors to talk to her and explain everything to her, so she helped me with everything. [Caregiver 5, Mother]

When caregivers were open with adolescents at an early age, they appeared to find it easier to trust them. One female adolescent explained that her mom told her when she was nine years old and that she did not blame her mother because her mother explained to her that she was infected by her father and that he was unaware of his status. However, another male adolescent explained that although his parents told him when he was nine, he '*held a grudge*' until he was 13 and that is when he realised that it must have been hard for his parents as well, illustrating a paradigm shift in his way of thinking. An adolescent explained how she felt because her mother lied to her:

I couldn't trust my mom because she like kept this from me, and then when it came out, it was like she pretended like nothing was wrong. She still does today. It's like nothing is wrong. [Female adolescent, Focus group 1].

Healthcare workers said that they motivated caregivers to talk to their adolescents and tell them that it was not their intention to infect them with HIV and to encourage the adolescents to talk about their feelings, but caregivers rarely did that. In many cases it was only the adolescent and his/her mother who knew that there were HIV-positive people in the family. One girl explained that not even her sister knew that she is HIV-positive. In other cases they had disclosed to the immediate family, but even in that family the topic was avoided, which was sometimes preferred by adolescents since they did not want to be reminded of HIV.

> *They don't bring up the topic, let's talk about people that have HIV and stuff. They don't do that.* [Male adolescent, 14 years]

Adolescents have to communicate with healthcare workers. When they come to the clinic on their own, they need to report any symptoms or problems they have experienced. Older adolescents were more likely to engage and ask questions than the young adolescents.

> *They also know what brings you to the clinic, to be able to talk with them, and not hold yourself back because they won't know your problem, what you think, I am that person who likes to talk, they ask what they have to ask and I am able to answer them.* [Male adolescent 4, 16 years]

> *Yes, I like to come to the clinic because sometimes I ask questions that I don't know about my sickness*. [Male adolescent, Focus group 4]

Healthcare workers reported that although some adolescents were very talkative, others were very quiet and rarely opened up to them. When they go on camps or outings, adolescents seemed more relaxed and healthcare workers said that they saw another side of them. Healthcare workers also reported that the adolescents who had been patients for longer tended to communicate more easily with them and talked about boyfriends/girlfriends, who broke up with whom and risk behaviours.

> *We accept that it is how adolescents are, if they do not want to talk today, then they do not want to, then you must leave them (laughing).* [Healthcare worker 1]

When an adolescent came with a caregiver, the healthcare worker sometimes had to see the parent and adolescent separately to ensure that the adolescent had the opportunity to talk about private things they did not want to share in front of their caregiver.

> *We will have a chat alone, we will talk about their sexual orientation, do they like girls, do they like boys, how is the friend situation, are they getting on well with friends, a lot of friends, not a lot of friends, how you're doing at school. We'll talk about what they*

understand about their illness, is it a problem, how do they feel about it. [Healthcare worker 3]

Healthcare workers mentioned that adolescents did not open up on every occasion and they needed to build a relationship with them first; other times they only opened up to certain healthcare workers, especially if they did not like a specific healthcare worker. Healthcare workers had to obtain information from the caregiver in cases where the adolescent did not share and eventually they had to see them both together, especially if there were issues to address. One healthcare worker mentioned that she encouraged adolescents not to keep things 'bottled up' and to tell her if anything was bothering them. Caregivers talked about how they encouraged their adolescents to also answer questions asked by the doctor. I, however, observed that when a caregiver accompanied an adolescent, the caregiver seemed to answer most of the questions. One of the healthcare workers mentioned that it was difficult to engage with the adolescents due to a lack of time. According to the adolescents, the nurses seemed to be very busy whereas the doctors seemed to have more time to speak to them. At times adolescents were seen by counsellors. One counsellor explains what happens in a typical counselling session:

I do counselling and ask what is their reason for being late, and when the viral load is high I would ask them if they are adhering to the treatment, how are they using their pills, if I see that they are not clear about something, I explain it again to them, and the ones who have issues from home, I'm the one who asks them "how are things at home, how are you coping, are there people who are mocking you about your status at home, maybe other children from your home are not HIV-positive so how do you feel about that," so they would talk. Some of them are not open and others are open. [Healthcare worker 4]

An exemplar identified was that social communication about HIV and HIV disclosure rarely happens outside the immediate family context. Very few adolescents had disclosed their HIV status to friends or girl/boyfriends due to a lack of trust and fear that they will be treated differently or that their friends will tell other people. Adolescents expressed that friends and girlfriends cannot be trusted with the information. One boy explained that he cannot tell his girlfriend even though they had been dating for more than a year. Others said they will only disclose when they are married.

I will never tell my friends no matter how much I trust them, because I know they will tell and the whole street will know. [Female adolescent, Focus group 2]

It's a short time. She can stab you in the back. If I am telling my girlfriend, it's been one year in a relationship, like she would turn it back on me that I am HIV. It must be like six

years or seven years, then I can tell her because she has been with me all the time. [Male adolescent, Focus group 5]

Although most adolescents did not disclose to their romantic partners, some had disclosed and had a positive experience. It seemed to be a relief when they had disclosed and some reported that they were supported by friends. It was, however, risky to disclose to friends due to the possibility of being rejected and some adolescents reported that they experienced rejection from close friends. Certain adolescents were not prepared or mature enough to deal with rejection by friends.

Like even some of the kids who have disclosed to friends, it didn't go very well. Like the one little girl we had, she is 12, and I think she disclosed to one of her best friends, and then her best friend didn't want to be her best friend anymore, and then after that she started having issues, and she's still having issues two years later. [Healthcare worker 3]

Adolescents communicated with peers at the clinic. Although very little of the personal communication seemed to be about HIV itself, there was a feeling of comfort in the group that made them feel accepted. Some adolescents communicated with each other outside the group since they went to the same school or lived close to one another. Others communicated on cell phones. Sometimes they also sent cell phone messages to one another to remind them to attend the clinic. However, they did not appear to talk openly about HIV in their social circles outside the discussions in the clinic groups.

With the 18 and 19 year olds, they do have, I would say a society whereby they communicate via WhatsApp. [Healthcare worker 6]

Healthcare workers gave individual health education about HIV, sexual relationships, contraception, drug use and other general adolescent issues such as making good decisions and career advice. Similar topics were addressed in the group discussions. One healthcare worker explained how she gave them 'homework':

So I gave them homework, to find out what is your viral load, your CD4 and your medication with the doses for the day. [Healthcare worker 2]

For the older adolescent boys in the Black community it was very important to talk about manhood. If they were isiXhosa, they needed to go for circumcision and initiation into manhood. Circumcision and initiation is part of their culture and they cannot become men and have a voice in the company of the men in their culture if they have not been initiated. They therefore liked to talk about these issues, especially sexual relationships since they saw sex as a necessary part of a romantic relationship. These older adolescent boys were more

forthcoming and more easily shared 'divergent' behaviours compared to the adolescent girls and the young boys group.

Communicating about HIV outside the immediate family was rare. Some adolescents reported that school teachers were aware of their status. Certain caregivers had informed the school about their child's status, while others did not since they were afraid that the teacher may accidentally disclose the information. In some cases, adolescents communicated with teachers at the school, for example, when they had to inform the teacher that they had to leave school early in order to attend their clinic appointment.

Adolescents therefore communicated with their caregivers, healthcare workers, friends, peers and sometimes educators; although most of them were very private and only communicated if they felt comfortable about the topic and if they felt they could trust the person.

4.3.1.6 Social facilitation

Social facilitation involves relationships, resources and support systems utilised by adolescents that facilitates self-management behaviours. It also includes support and resources within the family and outside the family, such as their peers, the healthcare system and the community.

Support from family was the most often discussed resource for adolescents. According to healthcare workers, adolescents with a good support system at home tended to do well in terms of being virologically suppressed. If the parents were also taking treatment, they usually reminded the adolescent to also take their treatment and vice versa. Some adolescents received support from caregivers and some from siblings or other family members. Yet, others were not supported.

> *If a child is not getting support from home, and when her siblings are mocking her, saying "you are the only one who is taking treatment here", so she won't be able to take care of herself, because she will normally say "I'm the only one who has this HIV in this house, why didn't you infect others with HIV and you only infected me." So if they don't get the support from home they will never use their treatment.* [Healthcare worker 4]

One caregiver explained how it helps if the whole family is aware and involved:

> *Then we had to tell them what is going on since they wanted to look after us and support us, and even my daughter so that she can go on holiday and not feel that she is different from the other children.* [Caregiver 3, Mother]

Some caregivers also supported their adolescents by reminding them to take their treatment, to eat healthily or by going to the clinic to fetch their treatment when they were busy e.g. writing

exams. Other family members, such as siblings or cousins, also provided support by helping with homework. Adolescents appreciated this support.

> *You stay with people you love, then they will make you happy, then you will even forget that you are HIV-positive. So, it's where you gain weight, it's where you gain health*. [Male adolescent, Focus group 5].

Stability in caregivers seemed to influence the support adolescents received. Some adolescents had to change caregivers, for example when a caregiver passed away. This left them feeling unsupported.

> *They will say if grandmother was still alive, I would have done this and that, grandmother's pass away has made my life stand still here, because now nobody has took over the way that she has.* [Healthcare worker 5]

> *Sometimes I get a little bit of support by my aunt, like sometimes it's like a myth. There was usually a person that used to guide me but, she was gone and now… I used to get advices from her like how to live how to… she was my role model.* [Female adolescent, Focus group 2]

In some cases, adolescents were orphans and had to live in a child-headed household. Their siblings did not have the skills to look after a child. They needed to learn from an early age to care for themselves without support or guidance.

> *He was a nine year old, so he chose to stay with the other one, although the other siblings were teenagers and they were working. So he opted to stay with them. So he is now happy, he is also having a key of the house, when he goes to school, he locks and goes. So with the rest, they were drinking, when he wakes up, he's just by himself, he has to do food for himself, but now he said he has learnt also to make an egg for himself (chuckle).* [Healthcare worker 6]

Some adolescents did not stay with their biological parents and were either cared for by relatives such as grandparents, siblings or foster parents. Healthcare workers reported that foster parents were supportive and sometimes took better care of the adolescents than some biological parents. If there were any concerns, it was reported to the social worker. Other healthcare workers mentioned that adolescents who reside with their grandparents or their aunties did not always do that well and some defaulted treatment. Sometimes the foster parents became 'fed up' with the adolescents and some adolescents even ended up staying with friends. A healthcare worker reported that on one occasion, a foster parent reported that the children in the house had sex with each other since they were not related. Foster parents

may have up to three children they are looking after. These adolescents may have been exposed to different things in their homes and it is difficult for foster parents to control their behaviour.

> *So they* [foster parents] *experience difficulties. And you will find out that maybe she took the child from a family whereby if the elders had liquor, they sleep together in front of them, so s/he learnt from that and saw it as something, so if s/he gets a chance to use it* [having sex] *they will*. [Healthcare worker 5]

As discussed previously, many adolescents did not have a good relationship with their parents. Parents sometimes did not know what was going on in the life of the adolescent because they did not spend time with them and most of the time this was due to their work schedules. Although some caregivers provided support, adequate discipline was lacking and sometimes the parents did not seem to have any control over the behaviour of the adolescent. Many times the adolescents seemed to be unsupervised in the house. Parents tended to think that their adolescents did not need them, especially when they were older. Although some adolescents came across as if they did not need the support of their parents, many still needed a lot of support and guidance. One 16 year old girl expressed her need to feel that her mother was interested in her life:

> *For me it's like when I'm sick, I get my mommy's attention the most. When I'm not sick, it's like you're just there, and then I have a small brother that's also there, I could kill that child, but anyway, it's like I'm not there. But when I'm sick, it's like "my baby are you fine? Do you need something?" They are always there by you, and the only sickness that throws me off is my fever. It like cuts me out, and then my mom is like "come, we're going to go put you in a lukewarm bath", then she baths me.* [Female adolescent, Focus group 1].

Some caregivers did not have the capacity to support the adolescent due to alcohol or drug misuse. One adolescent girl explained her father's behaviour when he was drunk:

> *My father will say "my child I'm going out now" and he will go and drink and then he will come back and ask me "why didn't you take your pills" and then hit me*. [Female adolescent, Focus group 3].

Relationships with healthcare workers and peers at the clinic seemed to be a source of support for adolescents. Some adolescents felt supported by healthcare workers since they knew their status and they could be open about it at the clinic. However, it still took time for them to build a relationship. Adolescents received support from peers in the groups at the clinic and healthcare workers explained that the adolescents were excited to come to the clinic and attend the group. The peers at the clinic provided comfort and a place where they felt accepted

since they had friends with similar problems and they felt that they were understood by their peers.

> *In this group, you can share your feelings, like how do you feel about the illness, and like outside you can't share it because you don't know who to talk to, and people will judge you*. [Female adolescent, Focus group 1].

The older adolescents seemed to know one another better since they had been together in the group for longer. Many of the young adolescents were still shy to speak in the group and some even verbalised that they did not trust everyone in the group. Sometimes it also took time for adolescents to build trust in the group to be able to share. Some of them would prefer just listening first and share in the group only later when they had attended the group regularly and had built a relationship with the other adolescents. Although some adolescents enjoyed being in the group, not all adolescents wanted to be in a group.

> *She does not really want to be part of the group, she does not participate. She will sit there while the others are talking and be busy on her phone the whole time*. [Healthcare worker 2]

Sometimes adolescents received support from healthcare workers that extended beyond clinic visits. In the past, both of the study sites took adolescents on outings or camps. This was something that the adolescents enjoyed a lot. It built relationships and also helped them to feel supported.

> *They really enjoy it. It's like a leadership camp, and they teach them like life lessons and skills, which they really enjoy. The thing is they don't talk about HIV all the time, it's boring (chuckles), and there is so much more to life. HIV is a big part of their life, but there are bigger things in life*. [Healthcare worker 3]

Support systems and resource utilisation outside the family or healthcare context were rarely reported. Only a few adolescents had disclosed to friends. Some received support from these friends and mentioned that they even reminded them to take their treatment. Most adolescents however had to hide their status from their friends and it became problematic when they went to sleepovers or camps since they did not always know when to take their treatment. Schools did not appear to offer any tangible support, but some caregivers and adolescents reported that teachers were supportive. One healthcare worker mentioned that there are peer educators at school who can support adolescents, but none of the adolescents mentioned making use of them. One adolescent explained how a teacher supported him:

So now almost every day at school she tells me did you take your medicine and all this stuff, but she just calls me to her table and so. [Male adolescent, Focus group 1]

Another adolescent felt that only certain schoolteachers were supportive and had understanding:

Or like sometimes at school when I tell my teacher we are supposed to get out of school at 1pm, she will say that I must finish my schoolwork first before I leave. Sometimes some of the teachers will agree with me that I can leave school to come here. [Male adolescent, Focus group 5]

Community support was translated in opportunities for adolescents to participate in activities. Healthcare workers and caregivers thought it would be good for adolescents to participate in activities or youth groups in the communities. These activities should not only be for HIV-positive adolescents and not associated with healthcare facilities to avoid stigma. Such opportunities for participation did not seem to be available in all community settings. Participation in sports, cultural activities or going to the gym may also have a positive effect. Adolescents tended to, in their own words, '*eat, sleep, and repeat*' and participation in activities may therefore also foster social relationships. One adolescent explained that he would like the support group to be in the community:

Maybe here in the community, and not always involving the clinic because most people don't like things that have to do with the clinic. [Male adolescent 4, 16 years]

In terms of accessing social support, adolescents staying in foster care and even those staying with biological parents seemed to know where and how to contact the social worker if they needed assistance.

They say it is not nice, sometimes even from the mothers that they stay with, they say these mothers become fed up, but even in that case they know what to do because they say they go to the social workers, because before they go to the foster care they start with the social worker, once the treatment becomes not good in the house, they go back to the social worker, and explain that I can't stay there, then the social worker will see what to do, maybe change them. [Healthcare worker 5]

The greatest source of support seemed to be the adolescents' immediate family. Although most adolescents reported to receive good support from their families, and some even from friends, not all adolescents were supported optimally. Several contextual factors may compromise their support structures. Support at the clinic from healthcare workers and peers were also reported, although most of the time it was only connected to clinic appointments which happened every one to two months.

4.3.2 Theme 2: Caregiver challenges

Self-management is not an individual process, but occurs within the context of the family and the community. There are reciprocal relationships between caregivers and adolescents that can either support or negate self-management. The processes in the family context or microsystem are called proximal processes and probably has the largest influence of HIV self-management.

The caregivers interviewed included five mothers and one grandmother. They reported several challenges and experiences from their perspective that I felt was necessary to discuss in a separate theme. While some adolescents mentioned that their fathers were involved and supported them, it seemed as if it were mostly mothers, aunties or grandmothers who were responsible for their care. Healthcare workers also reported several caregiver challenges that they had observed. These challenges were grouped into three sub-themes: knowledge and skills, socioeconomic difficulties and responsibilities.

4.3.2.1 Knowledge and skills

Although some caregivers were also living with HIV, they seemed to lack knowledge and confidence to talk to their adolescents about HIV. A repeated theme was that they did not have the knowledge to answer some of the questions the adolescents were asking. In the primary health care setting, HIV counselling and support is usually only provided to persons starting ART and thereafter only when needed. These caregivers may have received counselling several years ago and since forgotten some of the information. Treatment and guidelines have also changed and caregivers had not been kept up to date. One of the grandmothers who looked after an adolescent said that she was not even sure how her grandson was infected. She only took over the care of her grandson because his parents did not have the parenting capacity to look after him since they were both 'tik' (crystal methamphetamine) users.

Other aspects where caregivers lacked skills was communication with adolescents and how to handle normal adolescent behaviour and behavioural problems. Caregivers and adolescents relayed instances of normal adolescent behaviour.

> *She goes far sometimes without reporting where she's going, sometimes goes to the mall without saying. She is cheeky when I ask her to do something, she is short-tempered and become fed up easily*. [Caregiver 5, Mother]

> *I come back home, I did my duty, I went out, I partied, I got drunk, whatever, I come back. You can skel* [verbally admonish/shout]*. You're going to stop. I'm just going to ignore you. You are going to skel* [verbally admonish/shout]*, you're going to become irritated with*

yourself. I tell my mommy, you want to lock me up? I will fetch the Bill of Rights. I have a right to stay in this house, and the thing is this, I didn't ask to be here. [Female adolescent, Focus group 1]

A recurring assertion from adolescents was that they cannot talk openly to their parents, especially about sensitive issues.

You and I, like I can't tell you like look mom, I have a boyfriend, or I did this or mom, something or something, like broke my virginity or something like that. I can't talk to her about that stuff. It's like she just starts shouting. [Female adolescent, Focus group 1]

A central concern verbalised by healthcare workers was that many parents did not know how to discipline their adolescents on how to enforce and sustain rules and to meet out punishment or to hold them responsible for the consequences if they did not obey. Some adolescents started 'acting out' due to various reasons and caregivers did not always know how to deal with their behaviour. One healthcare worker explained how a grandfather struggled to manage the behaviour of his grandson:

But he's starting to act out now, he wants to do what he wants to do and his grandfather says he doesn't understand, he won't listen, he doesn't want to do anything, and he was saying well, the grandparents always take the little girl's [his younger sister who does not have HIV] *side, she is always so perfect, she does everything right, and he feels that he can do nothing right and so he acts out, which makes them more angry, and it just goes round in a vicious circle.* [Healthcare worker 3]

What came out strongly was that some adolescents appreciated their parents' strictness. It seemed to provide a sense of security. One female adolescent mentioned that if her mother was not strict, she might have acted out in a worse way and another male adolescent said that his grandmother is very strict, but that he feels it is acceptable.

My grandmother can be strict… but I feel it is right… when I did not do something and I go out to play then my grandmother gets angry… or if I do not drink by tablets, then my grandmother gets angry. [Male adolescent, 14 years]

Caregivers expressed that they needed a lot of support with disclosing the adolescent's HIV status. Many had to do this with the assistance of a healthcare worker. One mother shared her experience of disclosure:

It was not a nice feeling because I felt so powerless. I felt that I am losing my child, I felt what now, where to from here? [Caregiver 3, Mother]

Caregivers need to communicate to adolescents about a range of topics. Communication with adolescents about HIV and other normal development, for example, menstruation also seemed to be lacking. More than one healthcare worker mentioned that parents did not always motivate adolescents to study further.

> *The package is big since you must speak about HIV-related things and things not related to HIV and teach that to your child. What will work for you and what will not work for you and your health.* [Caregiver 3, Mother]

> *I find like a lot of them, their parents don't like push them in certain directions. Like they don't know how to apply for tertiary education, they don't know what options are available, they don't know what careers.* [Healthcare worker 3]

It appeared that caregivers needed skills to communicate to adolescents about HIV, other adolescent development issues and career planning. They also struggled to manage normal adolescent behaviour. Healthcare workers said that family problems were referred to a psychologist or social worker for parental guidance sessions, but that the sessions were not always completed since caregivers could not take off from work. A lack of parental communication skills may adversely affect adolescents' support for self-management.

4.3.2.2 Socioeconomic difficulties

Healthcare workers reported that the socioeconomic circumstances of adolescents who attended HIV services varied from middle-class to lower-class. However, there was a tendency for caregivers to be single mothers, aunties or grandmothers, especially amongst those interviewed. Families experiencing socioeconomic difficulties may not have the resources to adequately support adolescents living with HIV to self-manage. Caregivers often had to look after more than one child and most of the time they did not have a steady income. At times there was not enough money for food or they had to borrow money to pay for transport to attend the clinic. Adolescents wanted the things that their peers had and it is not always easy for caregivers to explain that they did not have the money to buy those things.

> *And if you listen to them, there are many things they do not understand. They want to have phones, they want things with earphones and music, but their parents cannot always give it to them. It is also things they have anger issues about, why they cannot have these things, they cannot understand that there are other priorities in the house.* [Healthcare worker 1]

One caregiver explains how she dealt with a situation where her adolescent wanted something:

> *If he says "mama can I get a play station" and I do not have money. I would say to him "look my child, please wait for at least 3 months, lets count this as the first month, and then in the third month I collect the money for the play station and give it to you*. [Caregiver 2, Mother]

Some caregivers could not afford to buy a phone for the adolescent to set reminders to take their treatment. One caregiver said that she had bought a phone, but that the adolescent lost the phone. If an adolescent struggled at school or needed additional support, there was no money to pay for extra classes. A number of caregivers reported that they would like to give more to their children, for example, for participation in activities so that they can remain motivated, but they could not afford to do so.

4.3.2.3 Responsibilities

Since caregivers seemed to be the greatest support for adolescents, their capacity to support may influence adolescents' self-management. Many of the caregivers spoke about the responsibility of looking after a HIV-positive child. The grandmother explained how she stopped working to look after the child and a mother explained how she always has to keep her eye on the child and how raising a HIV-positive child takes more effort than raising a HIV-negative child. More than one mother explained that it was a big decision for them to commit to take care of the child after hearing that the child was HIV-positive.

> *It is a decision you have to make, to say you take responsibility and not to give up. You must go on and sometimes people do not understand why you act a certain way, why you are so protective over the child.* [Caregiver 3, Mother]

Due to socioeconomic difficulties and the inadequate state-provided child allowance, many caregivers had to work. That meant that they were not always available to support or supervise the adolescent at the time s/he has to take their treatment. It is, however, important for caregivers to remain involved in the adolescent's life since they do forget to take their treatment and may do irresponsible things. Some caregivers explained that it is difficult for them to attend clinic appointments themselves (because they were also on ART) and to accompany the adolescent since the clinic times were on different days. To attend both appointments, they needed to take time off from work and they did not have enough leave days.

Caregivers have to manage their own emotions and support the adolescent. One healthcare worker explained that it is sometimes difficult for parents since they needed to deal with guilt feelings:

> *A lot of parents still feel a lot of guilt, because a lot of them didn't know they were positive, or maybe they didn't take their treatment properly, or back then they didn't even have treatment. So there is still a lot of guilt, and sometimes it's very difficult for the parents to speak about it with their kids and to say you're positive because I'm positive.* [Healthcare worker 3]

Caregivers who were also living with HIV had to take care of their own health, the health of their adolescent and sometimes also the health of their partners and other children. One mother said that a mother needs to be a pillar of strength since the adolescent looks to the mother as a role model. A healthcare worker explained that some grandmothers have physical and psychological health problems of their own:

> *Look, grandma complained a lot since she is old and her legs are painful.* [Healthcare worker 2]

Although one caregiver mentioned that the mothers sometimes supported one another, for example, if they were sitting in the waiting room at the clinic or hospital, there were no formal support groups for caregivers. A healthcare worker mentioned that they used to have a group for the grandmothers, but that they did not have the group anymore. Some caregivers had not disclosed to family members; healthcare workers reported that the caregivers, especially the grandmothers, struggled because they had nobody else to assist them with the adolescent. Caregivers conveyed their need for support.

> *Look, sometimes you also feel low, you get tired, but if you have someone to stand by you, you get the strength to continue with life.* [Caregiver 3, Mother]

Caregivers of adolescents therefore experienced their own challenges in taking responsibility for their own and the adolescent's care, which may affect their ability to support adolescents with self-management.

4.3.3 Theme 3: Putting the spotlight on HIV

This theme concerns how adolescents and their caregivers experience and manage HIV stigma. In isiXhosa there is no direct translation for the word 'stigma', so in this context it is described as discriminating against people who live with HIV or 'putting the spotlight on HIV'. One adolescent explained it as follows:

> *So it's something you wear, something that's like a shadow all over where you go, always being there for you*. [Male adolescent, Focus group 5]

4.3.3.1 Stigma

Stigma is still a significant barrier to obtaining adequate support within families, in the community and at healthcare facilities. Many adolescents and even caregivers did not want to use the local clinics in their residential area for fear that someone would recognize them at the clinic. Healthcare facilities were organised in such a way that HIV-positive people receive services separately. This separation of services was more evident in the community clinics than in the hospitals. Adolescents were afraid that others would recognise them at the clinic. One adolescent who received care at the tertiary hospital expressed her distaste when she had to collect her mother's medication from a community clinic.

> *I find it very insulting that the government are like making these special areas for us. It's like showing people that we are HIV-positive, and it's like my mommy is there, right, so now you are sitting there, and the people are looking for us and they know now those are the HIV-positive people. So they are basically telling people we are sick*. [Female adolescent, Focus group 1]

> *I don't feel very well when I'm coming to this side, because this side is for the people who have HIV, and I don't like that.* [Male adolescent, Focus group 5]

Certain healthcare facilities had signage that identified healthcare workers as providing a particular service which participants experienced as stigmatising. Although none of the participants mentioned stigma from healthcare workers, some avoided certain healthcare workers due to their association with HIV services. Even caregivers were afraid of being seen and tried to disassociate themselves from a particular service or context. One caregiver explained why she waits until the clinic is quiet:

> *Because if when I enter your office for example, and there's a sign at the door that says HIV, as we are waiting, there's a lot of us outside, and they see that I enter your door with that sign, they will say, "yho she is already finished" so I'll be scared to enter your room, I will wait for all these people to go, then I'll enter alone when it's empty*. [Caregiver 2, Mother]

Other support services were also avoided even if there were no signs to identify the service, due to the possibility that it may be associated with being HIV-positive. One caregiver reported that her adolescent stopped attending a support group at one of the local clinics because his friends started to ask questions about why he was going there. An adolescent girl explains how fear of stigma at the clinic can affect treatment adherence:

> *It will be when you don't want to go to the clinic, scared of being seen by other people, and you end up without treatment then you'll stop using them*. [Female adolescent 6, 18 years]

Treatment adherence is especially difficult if all the family members are not disclosed to. This means that the adolescent has to hide his or her treatment and sometimes will not take it if they are not alone. Many times mothers had not yet disclosed to their children that they are taking treatment and hid the treatment. It is only after disclosing to the children that the mothers could take treatment openly in front of them. Most of the time other family members did not know that the mother and adolescent were taking treatment.

> *Like even we have a boy who changed his meds, he is 14, and the mother actually came to speak to me to say it's a problem because the meds have to go in the fridge. Now everyone knows he is taking treatment, and they want to know why he is taking treatment, and so I suggested why don't you put it in a Tupperware, and then she goes no, no, but then people are going to look at it even more.* [Healthcare worker 3]

Schools can be significant in providing support for adolescents with chronic illnesses. Yet, schools seemed to be harsh environment with a lot of HIV stigma.

> *They will come and tell me that somebody said there are some children who are schooling with us, I don't know why they have to school with us because they are HIV-positive. They are supposed to be schooling on their own school, not with us*. [Healthcare worker 6]

> *Maybe the school children will laugh at you and during the break they will point at you showing others, mocking and swearing at you.* [Female adolescent 6, 18 years]

Some examples of colloquial labels for HIV were provided. One adolescent boy explained that school children said that a person has 'salt' when they suspect s/he has HIV:

> *Most people have assumptions about you, say for example you are slender and they will know that you are caused by salt, it has finished him*. [Male adolescent 4, 16 years]

An adolescent girl explained how she felt after her aunt told the teachers about her HIV status:

> *So now every time when I ask them, "may they please dismiss me early like today?", so it was like all the teachers were looking at me like there was something they were talking about inside, which I do not know*. [Female adolescent, Focus group 2]

It was evident that the fear of HIV stigma influenced adolescents' self-management decisions, behaviours and their general quality of life.

4.3.3.2 Fears of rejection

Adolescents and caregivers expressed fears of being rejected. Many of the examples provided by them were hypothetical in nature - how they imagined people would react when they learned that they were HIV-positive. They also feared that if they told a person, that

person will tell other people. The biggest fear seemed to be that of being treated differently. This was especially difficult for adolescents since they are looking for acceptance and want to fit in. In some families HIV was still seen as taboo. One adolescent girl said that her family and friends would treat her like an animal if they found out she was HIV-positive. Others felt that people will think they are 'freaks of nature' or that they will infect them with the virus. They thought people will, therefore, not come close to them or even chase them out of the community.

> *Some communities don't want HIV-positive people, they sometimes chase them away and say they cannot live with someone who is like that... it's like you are going to infect them.* [Female adolescent 6, 18 years]

Perinatally-infected adolescents felt that people may think they had been promiscuous.

> *I'm like ja* [yes]*, and you know, it kind of sucks because you can't like stand up for yourself and be like well, this is what it is and stuff like that, because people are going to look at you like oh, this guy sleeps around, I knew it by the way he looks already*. [Male adolescent, Focus group 1]

Those adolescents in romantic relationships feared that their partner will break the relationship off and inappropriately disclose their status. Thinking of having to disclose their status to a girlfriend or boyfriend prevented some adolescents from engaging in romantic relationships.

> *Because they will dump you just because of your status*. [Male adolescent, Focus group 5]

> *So it was always an issue, and now when you are a teenager and you're like dating girls, you're like you don't know whether to tell the person or not. You're like should I tell, should I not? In the end you end up breaking up with the person because if I tell this person she's going to go.* [Male adolescent, Focus group 1]

Adolescents therefore anticipated the thoughts and reactions from others should they know their HIV status. Their thoughts and feelings indicate that many of them have internalised HIV stigma.

4.3.3.3 Telling lies

Adolescents and their caregivers adopted strategies to cope with the HIV stigma they experienced. An exemplar identified was that one of the consequences of HIV stigma and the fear of rejection was that it resulted in telling lies to, for example, family members, friends, romantic partners and school teachers. This caused stress and frustration for many adolescents.

> *I have to lie continuously to cover up my illness, and it is not nice because sometimes someone will talk about it, but I cannot speak to anyone since I cannot tell them about it.* [Female adolescent, Focus group 1].

A mother explained how she helped her child to lie to his friends:

> *When I get to him while he is still with them I would say "my child it's school tomorrow, so you need to get home early" or even say "come I want to send you to the shop, you will come back to your friends", because he is sitting with them. When he comes back, he would take his pills then I give him R1 for his friends to think that it's the change from the shop.* [Caregiver 2, Mother]

Caregivers confessed to telling lies to their children about their diagnosis because initially they could not tell them the truth. Adolescents seemed to follow the example set by their parents since many adolescents reported telling lies to their friends at school in order to explain why they had to attend clinic appointments. They said that they had some kind of other illness, for example, sinusitis, eczema or asthma.

> *What will make it better is if they stop asking me why are you absent, because I am not lying, but if I have to I will, and I'm a really good liar, if I may say so myself*. [Female adolescent, Focus group 1].

Stigma therefore still continues to affect people living with HIV. Many try to cope with it in their own way, but the continuous feeling of being stigmatised, whether it is actual or perceived, may adversely affect their quality of life.

4.3.4 Theme 4: Healthcare system

This theme concerns information provided by participants regarding the structure and functioning of the healthcare system as well as participant preferences. I spent a prolonged time collecting data and made my own observations that I wrote down as field notes. Adolescents need to collaborate with healthcare workers in order to self-manage their chronic disease. This collaboration depends on the relationships they have with healthcare workers as well as the structure and functioning of the healthcare system.

4.3.4.1 Adolescent preferences

Adolescents and healthcare workers mentioned particular preferences related to the healthcare system. Adolescents wanted clinic appointments to minimally affect their schedules and routines. They do not want to come to the clinic on holidays and when they come, they prefer not to wait too long. They want healthcare workers to treat them with

respect. Emphasis was placed on confidentiality and trust during consultations and within the groups or clubs.

Adolescents appreciated it if the clinic was well-organised, that their own space was available, that staff were helpful and that activities were provided for them. It was apparent that they do not want to talk about HIV all the time. They like to talk about other things (particularly those topics that interest adolescents such as sex), listen to music and be provided with some food or refreshments when they come together. Outings or camps organised for them were appreciated. Some enjoyed coming to the clinic, while for others it interfered with their school programme and they mentioned that they would prefer to attend at a time convenient to them, for example after 16:00, or even use a private doctor if they could afford it.

> *Going to the clinic most of the time is boring sometimes, because you lose lots of things at school, because some of the subjects are done at the same time that I have to be at the clinic*. [Male adolescent, 16 years]

Healthcare workers mentioned that building a relationship with adolescents is important. This necessitates time, commitment and continuity.

> *Yes, because if you know they went through some sort of breakup or whatever this month, then next month you can ask so how are you doing, how are you coping with that?* [Healthcare worker 3]

Adolescents also had preferences for certain healthcare workers. However, it was not always possible to give them a choice.

> *She* [the psychologist] *wasn't working here anymore, so she landed up with someone else, and obviously they didn't bond well, so after the first two sessions she stopped going. She didn't want to go anymore. It's difficult also to pair people up, if they bond. You can't predict who is going to bond with who.* [Healthcare worker 3]

One healthcare worker explained that if they became frustrated with an adolescent they referred the adolescent to a colleague. Sometimes the adolescent bonded better with the colleague or they just had a different approach that worked. Some older adolescents expressed that they preferred coming to the club and that they did not want to be transferred to the adult services. At the one site there were two groups for adolescents over the age of 18. A number of adolescents at the other site were transferred to the adult service, but still attended the adolescent group discussions. In most cases, it was because they built a relationship with the healthcare workers and other peers.

So they do enjoy, like the 21 year olds, they say Sister, we don't want to go out from the club because we get a lot here, because at times, our emotions are tender, we are getting into relationship and out of relationship, but if I come here and then I talk to you whatever I came across, my boyfriend and all that, I go happy home, because I can't talk with my mother about boyfriend issues. [Healthcare worker 6]

Clinic attendance may be improved if services are focused on the needs of adolescents. This may, however, require understanding and effort on the side of healthcare workers and government funding in order to provide a space and staff dedicated to adolescent care.

4.3.4.2 Clinic or hospital functioning

Part of adolescent HIV self-management is navigating the healthcare system. Healthcare services, therefore, need to provide an adolescent-friendly system that makes it easy for adolescents to use. In this section, I highlight some of the aspects of clinic or hospital functioning that could affect adolescents' motivation to access services.

Times for clinic appointments need to enable adolescents to attend. At the tertiary hospital, adolescents attended in the mornings and they seemed happy with the arrangement since they were provided with a sick note for school. In the primary health care clinic setting the time of the clinic was in the afternoon so adolescents did not have to miss school to attend the clinic. One healthcare worker felt that the afternoon clinic was not practical:

I think ideally the idea of an afternoon clinic is very nice, but it's not practical. Like a lot of the times the kids don't go to school anyway, and the point of doing an afternoon clinic is to make them go to school. A lot of the kids go to school outside of where they stay so they have to take transport there and transport back, so it's not practical. [Healthcare worker 3]

Another problem with the afternoon clinic was that many adolescents attended school far from the clinic, causing them to be late for the appointment and missing the group sessions. One healthcare worker explained that she still provided sick notes for the adolescents to take to school even though they came in the afternoon. This caused problems when another healthcare worker took over the adolescent group and refused to provide sick notes.

No man this nurse here next door is not treating us well, because she shouts at us, like for example I was asking her for a paper to present at school [proof of attendance] *and she shouted at me, and asked me why didn't I go to school, while the previous nurse was not doing like that.* [Female adolescent, Focus group 2].

As the abovementioned quote illustrates, healthcare workers' practice is not consistent and understanding. They may not understand the adolescent phase or accommodate adolescents by being flexible. Some adolescents may not come on their date or at the correct time and

that needs to be managed appropriately by healthcare workers as to not discourage adolescents from attending. Ways in which some healthcare workers tried to make it easier for adolescents were to be flexible in terms of when they can come to the clinic. They would still see the adolescents, even if they did not come on the scheduled appointment days and tried to give them other treatments such as contraception on the same day so that they did not have to come on a separate day.

> *One tries to give them everything with their ARVs, contraception and advice, but even with contraception you have to put in a lot of effort to get them to be adherent to go for their injections so it does not really work.* [Healthcare worker 1]

Another concern is the support group structure and if gender-specific or mixed gender support groups are more appropriate. There were not so many adolescents at the tertiary hospital and the groups were therefore mixed. It seemed to work well since many of the adolescents had been in the group for a long time and made friends in the group. At the primary health care clinic, there were separate male and female groups which made talking about sensitive topics easier.

In terms of collection of medication, the adolescents had to submit their folders at the hospital pharmacy after seeing the doctor and wait for their treatment. At the primary health care clinic, the treatment was pre-packed. That reduced their waiting time leaving more time to engage with the group.

With regard to continuity of care and healthcare workers, it was clear that adolescent-specific care and group facilitation were problematic due to the additional costs of having to employ persons or recruiting persons willing to take on the responsibility. At the primary healthcare site no healthcare workers were trained to work with adolescents and those working with the adolescents did not volunteer to do so. I observed during the process of data collection that the adolescent clubs at the primary health care site were not well organised. Some days nobody prepared the folders or the pre-packed medication and there was uncertainty as to which healthcare provider should see the adolescents. The primary healthcare site had had a dedicated doctor and counsellor who resigned a few months prior to data collection. The remaining healthcare workers indicated that the doctor and counsellor leaving had a negative effect on the adolescent service and attendance.

> *All that has fallen apart. Now there's nobody who has something tangible that can hold them to the support group and for them to say it's nice on that support group because we are doing something.* [Healthcare worker 5]

> *So now they say they don't see why they should attend because* [doctor's name] *is no longer at the clinic, she's the one who was looking after them, but a few is coming, but it's not the same as before.* [Healthcare worker 4]

Although both sites experienced challenges, there was an effort to provide an adolescent-friendly service, which is not necessarily available in other clinics. Healthcare workers reported that most of the other sites they have worked at did not have separate clinic days or adolescents and there were no support groups. One of the healthcare workers mentioned that in the private sector, adolescents are very isolated:

> *Like even sometimes when I did locums, like GP locums, you'd see a kid and you'd pick up similar things like that, I'm the only one with HIV, I don't know anyone else, I'm the only one who has to take tablets, I'm the only one that's different. We find a lot of our kids have that, but at least here, they kind of know that there are other children who have the same problem, even if they don't know them personally*. [Healthcare worker 3]

It may, therefore, be challenging to find the resources and healthcare workers with a deep understanding of adolescent needs in order to support continuous adolescent-focused services.

4.3.4.3 Healthcare worker attitudes

Healthcare worker attitudes may influence adolescents' willingness to attend services. Adolescents wanted to be treated with respect. Some of them mentioned that the staff did not treat them with respect and shouted at them, especially when they were late for appointments. Others felt that healthcare workers took too long to attend to them.

> *We would like to be treated fairly/good and when we ask something the nurses shouldn't shout at us, they must answer us well.* [Female adolescent, Focus group 2]

> *If you ask for help, they take their time, they don't do things fast. You wait for two hours or something.* [Male adolescent, Focus group 5]

The attitude of the healthcare workers and their willingness to assist adolescents was seen as important. Some adolescents distinguished between the attitudes of doctors and nurses. Adolescent experienced nurses to be very busy and were more likely to speak to doctors. This was especially mentioned at the primary health care clinic where nurses had to render a service to other patients and had the additional administrative tasks related to managing the adolescent clubs.

Some nurses are like, it's depending, they are not the same. Like other ones are cheeky, but the doctors are okay. But the nurses, they are like speaking like rudely. [Male adolescent, Focus group 5]

Adolescents seemed to be very sensitive to how they and their parents were treated by healthcare workers; emphasising the point that healthcare workers need to understand how to work with adolescents. A caregiver explained that her adolescent did not want to attend the clinic anymore after a doctor confronted her mother about her high viral load. It is difficult for caregivers to motivate adolescents to attend the clinic if something happened that made it uncomfortable for them.

It is how she confronted me in front of my child. This is what I am saying. An HIV child looks up to her mother. She is very protective over her parent. [Caregiver 3, Mother]

Healthcare workers said that it is important that the person who works with the adolescents wants to work with them. They need to speak to the adolescent on their level, be non-judgemental and approachable.

You don't regard yourself as a professional somebody, you are just an aunty in the township. Then you will get everything out. Just to talk their language (laughs), ja, and ask them about things that are happening in their life in their own language, their level. [Healthcare worker 6]

It is being friendly to them and where you are with the young one, you need to be young as well, and when you are with an adult you become an adult yourself. So you need to be approachable and love these children, because if you always wear a long face they will never talk anything with you. If they are 13 years you need to be 13 as well. [Healthcare worker 4]

Adolescents said that they do not share private information if they do not feel comfortable or if they feel that the healthcare worker will be angry with them. Healthcare workers should have realistic expectations of adolescents, be understanding about where they are at and know how to communicate with them.

If they can understand peer pressure, there is this thing called stage [Sic]*, if they can stop speaking impolite sometimes, because you are also a human being and you do not forget what has been said to you, you think about it and feel like nobody cares about you, the way you talk to someone…To be able to communicate because you can get some counsellors who just speak like "why are you not taking your pills, why are you like this, why are you*

not behaving well," because they didn't listen to your problem first as to why are you behaving the way you do, so they just ask what they ask. [Male adolescent, 16 years]

The way the healthcare system functions, as well as the attitude of the healthcare workers, therefore, plays a key role in either supporting or hindering self-management processes and behaviours in adolescents. It is important that the functioning of the healthcare system accommodates the unique needs of adolescents. Healthcare workers need to understand the adolescent stage of development and how to appropriately communicate and manage them in the context of the healthcare service.

4.3.5 Theme 5: Factors influencing self-management

There are several factors that might influence self-management. This theme relates the factors that can influence day-to-day self-management processes and behaviours of adolescents that was identified though the interviews and focus groups. The focus of this theme was to identify demographic and other factors that should be included in the questionnaire that was used in the fourth phase of the study.

4.3.5.1 Disease and treatment characteristics

Predominantly adolescents were in good health. When they reflected on past illnesses when they were younger, most reported that they had had tuberculosis (TB). Concerning treatment, repeated statements were that taking the tablets made them nauseous, that the tablets did not smell nice, were big and got 'stuck' in their throats. Some also complained of side-effects. The most common side-effects were dizziness, nightmares, headaches, undifferentiated pains and a feeling of sleepiness or 'feeling high' which were probably the neuropsychiatric side-effects of efavirenz. The frequency of taking treatment was problematic for some adolescents, especially if they were on twice daily doses.

You see, it tastes ugly, it smells ugly, it's hard to swallow, and when I drink it, I get a little bit better, then I'm like, like I drink my medication at six o'clock, like around seven o'clock, I will be like dizzy. There will be like stars around me and I'm like I need to sit down quickly. [Female adolescent, Focus group 2]

The fact that adolescents mostly felt well, that it was not nice to take the treatment since they experienced side-effects and sometimes forgot to take their treatment in the mornings were presented by some as reasons for omitting a dose.

4.3.5.2 Individual differences

An exemplar identified through interviews with healthcare workers was individual variability between adolescents. In general, they did not distinguish between adolescents who live with

HIV and other adolescents in the community. The HIV-positive adolescents also displayed 'normal' adolescent behaviours. I specifically asked about any physical and developmental delays and in general, healthcare workers did not report any trends. One healthcare worker said the following:

> *HIV is very variable in how it affects different kids. Like some kids, they get sick all the time, and other kids are 100% fine on ARVs, and some kids are so growth-retarded. Like you will have a 14 year old boy who looks like he is 10. Even the other day I saw a little boy who is four and he looks like he is two. So sometimes it's quite severe, just because of HIV, and sometimes they are 100% normal, you would never say, even some of them, the ones that are not on ARVs.* [Healthcare worker 3]

Healthcare workers mentioned that many of the children either have learning disabilities, memory problems, are hyperactive or struggle at school. However, according to the adolescents and caregivers, the adolescents did not experience problems at school. Only one adolescent expressed that she struggled in school and that it was 'difficult' and her caregiver explained that she had a learning disability. It became apparent that many of the adolescents were in a lower grade than they were supposed to be. This may not always have been related to cognitive ability, but also circumstances such as a poor schooling system, changing schools or ill health. For example, one adolescent mentioned that she failed a year because she had TB and could not attend school for some time. Another adolescent explained that stress due to being HIV-positive can also affect school performance:

> *Maybe when you are stressed by the fact that you are HIV-positive, so sometimes it becomes difficult even to write at school, and thinking, things like that*. [Female adolescent 6, 18 years]

Healthcare workers reported that many adolescents experienced emotional problems such as depression. Some also had other behavioural problems, for example, aggressive behaviour and emotional outbursts. The personality of the adolescent seemed to play a role.

> *Some of them, because they want to get on with their lives, they are focussed, they know where they're going, how they're going to get there, but a lot of other kids need a little bit of help*. [Healthcare worker 3]

I noticed that older adolescents were more active in participating in the focus groups and interviews. It seemed that the adolescents' ability to engage in a conversation and their critical thinking ability increased with age. They were more likely to describe various self-management behaviours in detail compared to younger adolescents who mostly only referred to '*taking treatment every day*'.

Healthcare workers reported that some adolescents went through different phases. When they are younger they tend to listen to their parents and are very obedient. As they grow older, around the age of 11 to 12 or sometimes earlier, they start questioning why they have to take treatment and tend to become non-adherent. Then, around the age of 15 and older, when they are exposed to different groups of friends and social circles, they start experimenting and want to stay out late. Some even become rebellious at this stage, which also leads to non-adherence. This may mean that self-management does not necessarily increase gradually with age, but that other contextual factors influence the self-management of adolescents as they grow older.

4.3.5.3 Family context

Adolescents came from various social backgrounds. Many did not live with biological parents, but with relatives or foster parents and many reported to have changed caregivers. Support structures and family routines varied. Supervision was not always possible due to caregiver work schedules or in some cases the absence of a responsible caregiver. According to healthcare workers, adolescents with good support structures at home, where HIV was discussed openly in the home and where they had disclosed to family members, generally did better, for example, they were virologically suppressed.

Some adolescents were exposed to physical abuse and child molestation. A healthcare worker reported that one of the adolescents in the clinic fell pregnant and that they found out that she was molested by a family member.

Each adolescent also has a unique story and circumstances. A healthcare worker related the story of one adolescent:

> *He was in between the mom and the father and the grandparents. They all split up and then basically I think his sister died when she was little, she was like eight or something, the mother completely fell apart and he stopped taking his meds. He has defaulted time and again and again and again. He landed up in hospital like a year or two ago, but since then he has managed to pull himself together on his own basically without his mother's help, with the help of his grandmother*. [Healthcare worker 3]

These family contextual factors may influence adolescents' support for self-management.

4.3.5.4 Healthcare system functioning

The functioning of the healthcare system influences the adolescents' experience of the service. Adolescents are very sensitive to healthcare worker's attitudes. If adolescents enjoyed it at the clinic, they were more likely to remember their appointments. Even if they did not particularly enjoy attending the clinic, a well-organised service where they did not have

to wait long and where they were not exposed as being HIV-positive, positively affected their attitude towards attending clinic appointments. The adolescent support groups or clubs seemed to be a good source for information-sharing, providing education about HIV and for fostering peer support. It also creates a space for reinforcing the correct messages about HIV and risk behaviours.

4.3.5.5 Community influences

Stigma in families and in the community is a barrier to self-management behaviours for adolescents and caregivers. Adolescents, especially older adolescents, are exposed to drugs and alcohol since it is freely available in some families and in the communities. Violence, gangs and bullying are common and may cause additional stress since adolescents may not feel safe. Caregivers may not want their adolescents to participate in community activities due to safety concerns.

Bullying was common at schools and the teachers were not always able to support adolescents, leaving them to manage it themselves.

> *Also at school, the kids are being bullied. Like this one girl didn't want to go to school, and then there is lots of gangsterism, even at the school that they go to.* [Healthcare worker 3]

> *I don't like the way those children are talking to me it's like the end of the world when they tease me, it's like I have no belongings to myself sometimes*. [Female adolescent, Focus group 2].

Many of the adolescents also reported receiving corporal punishment at school. Some teachers had beaten them with rods or plumbing pipes on their hands and under their feet. These community influences and behaviours by teachers do not contribute to creating a safe and supportive school environment for adolescents.

4.4 DISCUSSION OF KEY FINDINGS

Five main themes were identified through the interpretive analysis process: Self-management process and behaviours; Caregiver challenges; Putting the spotlight on HIV; Healthcare system; and Factors influencing self-management.

Self-management in this context is realised through processes and behaviours such as knowing and understanding; believing and valuing, self-regulation, coping, communication and disclosure and social facilitation.

The sub-theme of knowing and understanding can be captured as an awareness of HIV that does not disturb or hinder and facilitates acceptance. This process of knowing and understanding their illness seems to be facilitated through discussions with caregivers and

healthcare workers, although this may be hindered by the sensitivity of the topic. Awareness of the illness further results in acquiring more specific knowledge such as why they have to take treatment and what behaviours are healthy or risky. This seemed to be facilitated more through group discussions or individual discussions with healthcare providers. Healthcare workers felt that the knowledge of adolescents was inadequate and that many did not understand the long-term consequences of their illness, the importance of taking treatment and had little knowledge of risk behaviours. Adolescents appeared indifferent to biological markers or treatment outcomes such as their CD4 count and viral load.

Believing and valuing relates to how being HIV-positive changes adolescents' views of themselves and the future. A central concern of adolescents was that taking treatment made them feel different and they longed to be normal. Caregivers and healthcare workers tried to motivate adolescents through telling them that HIV is just another illness and that they can still live normal lives. The beliefs of caregivers seemed to strongly influence those of adolescents. Caregivers were more likely to narrate spiritual beliefs as a beacon of hope, whereas adolescents were more focused on science as a cure for HIV is imminent or that the human race will evolve.

Self-regulation encompasses specific skills such as planning, evaluating, and goal-setting. Participant narratives related to self-regulation focused more on the medical management of care than emotional and social management. Healthcare workers doubted whether adolescents have these skills. The self-regulation processes identified included remembering to take their treatment and attending clinic appointments, although it was evident that they sometimes struggled to remember and integrate medical management into their daily routines. Older adolescents were more likely to attend clinic appointments on their own. Healthcare workers reported that adolescents usually attended appointments, but not always on the scheduled dates. Some adolescents shared how they made decisions about whom to disclose their status to. It was apparent that certain adolescents were engaging in risk behaviours such as drunkenness and having sex without using a condom. Negotiating to use condoms was challenging for some, especially when in a relationship. Some had the need to fit in and not allow HIV treatment to hold them back. Adolescents' goals were general with few specific to treatment outcomes.

Adolescents mostly used emotion-focused coping strategies such as avoiding discussions or negative conversations about HIV. Those who received support from family and where HIV could be discussed openly within the family, seemed to cope better. Some attempted to escape by using substances, especially when their status was first disclosed to them; while others distracted themselves though other activities.

It was perceptible that communicating about HIV was difficult for parents and adolescents. Many had not disclosed their status outside the immediate family. The main barrier to communication and disclosure was a lack of trust. Healthcare workers mentioned that adolescents do not always communicate to them in a consistent way. Peer groups formed a platform for communication about their illness and general adolescent issues.

The family was the primary resource facilitating self-management in most cases. Some adolescents lacked support due to changing caregivers or family problems such as alcohol misuse. Adolescents expressed that they appreciated care and understanding from caregivers or family members. Healthcare workers and peers at the clinic were other sources of support although this support was only intermittent. For some it was the only time they could acknowledge that they are HIV-positive. Few adolescents were supported by friends or teachers at school. Healthcare workers and caregivers felt that engaging in community activities would be beneficial, although such opportunities seemed to be scarce.

Caregiver challenges included a lack of knowledge about HIV and skills to communicate with adolescents and manage their behaviour. Caregivers and healthcare workers reported socioeconomic difficulties since most caregivers were single mothers, aunties or grandmothers. For caregivers it was a great responsibility to look after an HIV-positive child, since some were also HIV-positive, had few sources of support and had to earn an income by working. These challenges may affect the capacity of caregivers to support adolescents with self-management.

Caregivers and adolescents were very careful to ensure that their status remains a secret due to experiences and beliefs about stigma. Healthcare facilities where HIV services were separated were perceived as stigmatising. Participants feared stigma and rejection from family, friends and the community which usually resulted in telling lies about why they attend clinic appointments and included hiding their tablets. Schools were identified as a harsh environment with pervasive HIV stigma.

Adolescents had specific preferences for healthcare services, mostly related to being treated with respect and short waiting times for services. Peer support groups or clubs was identified as a positive aspect of care. Providing continuity of services to adolescents was challenging due to resource constraints. The most important aspects of providing adolescent-friendly care appeared to be that healthcare workers need to be conscious of the needs of adolescents and know how to communicate with them.

Several factors that may influence self-management were identified and categorised into disease and treatment characteristics, individual differences, family context, healthcare system functioning and community influences. Some adolescents disliked taking tablets due

to the taste and size of the tablets, while for others the frequency of taking tablets was problematic. It was clear that there are individual differences amongst adolescents who live with HIV that may or may not be attributed to the effect of HIV on development, their personality, the adolescent's stage of cognitive/social/emotional development and the family context. It was also apparent that the community, especially schools where bullying was rife, in most cases did not provide a safe and supportive environment.

4.5 SUMMARY

In this chapter, the findings on how adolescent HIV self-management was realised in a South African setting were presented. Five themes were identified, described and interpreted in the light of the study's theoretical framework (IFSMT). The findings of the qualitative phase informed the next phase of the study which was to generate items to be included in a questionnaire to measure adolescent HIV self-management. In the next chapter I will discuss the findings in relation to the literature and illustrate how the initial items for inclusion in the questionnaire were identified.

CHAPTER 5
DISCUSSION, LITERATURE CONTROL AND ITEM GENERATION

5.1 INTRODUCTION

The second aim of the research study was to identify items for inclusion in an instrument to measure HIV self-management in adolescents living with HIV based on the findings of phase one, known self-management (SM) models, other similar instruments and a literature review. In this chapter, I situate the themes within the current literature and then relate the sub-themes of SM processes and behaviours to the literature and SM theory in order to contextualise adolescent HIV SM. Through this process a list of items were identified that were refined further in the third phase of the study.

5.2 DISCUSSION OF FINDINGS FROM THE FIRST PHASE

I discuss the findings from the first phase of the study under each of the identified themes in relation to the current literature. It is important to keep in mind that the participants of this study may not necessarily have observed, experienced or demonstrated all the self-management processes, behaviours and skills represented in the literature. This does not, however, mean that these are not important components of self-management in this context. It may be that the participants have never been exposed to or educated about these concepts. I therefore aim to integrate the theoretical constructs in the discussion in order to demonstrate where there may be gaps in the self-management of adolescents, while trying to keep a balance between participants' experiences and the literature.

5.2.1 Self-management processes and behaviours

Self-management processes and behaviours had the following sub-themes: knowing and understanding; believing and valuing; self-regulation; coping; communication and disclosure; and social facilitation.

5.2.1.1 Knowing and understanding

Active engagement in self-management requires adolescents to know their HIV status. For perinatally-infected adolescents, it implies that someone should disclose their status to them and a process of disclosure is usually followed, with full-disclosure by the age of 10 or 11. The WHO (2011:12) recommends that children of school age, namely, those with the cognitive skills and emotional maturity of a normally developed child of 6-12 years, should be told their HIV-positive status. Adolescents in the present study knew their status since it was part of

the study inclusion criteria. However, based on the narrative accounts of adolescents, caregivers and healthcare workers, HIV disclosure was a central concern. Caregivers struggled to disclose the adolescent's status to him/her and postponed it for as long as possible. Some caregivers asked healthcare workers to assist them with disclosure. It was also apparent that participation in the support groups may have facilitated disclosure for some adolescents. Low disclosure rates among perinatally-infected adolescents have been reported in studies in Africa (Abebe & Teferra, 2012:1097; Biadgilin, Deribew, Amberbir, Escudero & Deribe, 2011:1; Brown, Oladokun, Osinusi, Ochigbo, Adewole & Kanki, 2011:1053). Only 70% of a sample of adolescents in the Eastern Cape, South Africa, aged 10-19 knew their HIV status, with 39.4% of 10-14 year olds not knowing their status and 8.3% of 16-19 year olds being unaware (Cluver, Hodes, Toska, Kidia, Orkin, et al., 2015:S57). A qualitative study of the lived experiences of older 16-17 year old perinatally-infected adolescents in the Eastern Cape, reported that disclosure was a once-off event that was very emotional. However, adolescents reported that disclosure facilitated making sense of medical management activities such as taking treatment and attending clinic appointments (Jena, 2014:60).

As with most behaviourally-infected adolescents, some perinatally-infected adolescents may be diagnosed in adolescence, after becoming ill and not necessarily at birth. One adolescent in the current study described that she learned her HIV status when she was diagnosed with TB. She went to the clinic on her own and was diagnosed with TB and HIV. Her mother only disclosed to her that she might have been infected at birth after she had been diagnosed at the clinic. According to Ferrand, Corbett, Wood, Hargrove and Cowan, et al. (2009:2039), an epidemic of older perinatally-infected survivors is emerging in sub-Saharan Africa with many "slow-progressors" only diagnosed in late childhood or adolescence. Chronic morbidity may be higher amongst perinatally-infected adolescents who are diagnosed late (McHugh, Rylance, Mujuru, Nathoo, Chonzi, et al., 2016:275).

Awareness of one's HIV status is followed by information about what the disease is, how it is transmitted, possible complications, consequences and treatment options (Van Staa, 2012: 100). Learning about the condition and your health needs is a self-management process (Schulman-Green et al., 2012:139). This goes hand in hand with understanding how to prevent complications, what lifestyle and behaviours are healthy (Sattoe et al., 2015:709), and taking ownership of the individual's health needs (Schulman-Green et al., 2012:138). Adolescents have an evolving capacity to understand HIV, which should be recognised by parents and healthcare workers (Mburu et al., 2014:5). Yet, the study findings indicated that some adolescents may have limited understanding of HIV and the long-term implications thereof. Older adolescents appeared to have more insight and understanding about HIV

compared to younger adolescents. Denial about HIV, especially because they feel healthy, may further prevent the acquisition of disease- and treatment-specific knowledge.

Disease specific knowledge is important for medication self-management (Barnes et al., 2013:314) and treatment knowledge and literacy are essential for adherence (Modi et al., 2012:478). Knowledge required to practice chronic illness management and to cope with different situations forms the foundation of self-management (Karlson, Arman & Wikblad, 2008:562). Adolescents generally seemed to know why they needed to take ART, the times of taking it, that they should not take it with other drugs or substances and what will happen if they do not take it. Few knew the names of their tablets and there was uncertainty of whether they can take ARVs with or without food. As mentioned before, the adolescents who participated in the first phase of the study all seemed to be infected perinatally. Barnes et al. (2013:314) found that behaviourally-infected and older adolescents in the United States had more knowledge of HIV.

Behaviourally-infected adolescents were also more likely to report discussions with healthcare providers about risk reduction, for example, using condoms. If a person is on ART, knowledge of the treatment itself, times of taking treatment, management of possible side-effects, adherence to treatment and knowledge about what to do when a dose of treatment is missed is important (Swendeman et al., 2009:15; Sattoe et al., 2015:709). Some adolescents reported that they did not know the names of their tablets due to them being changed frequently. Failure to understand what the healthcare provider tells adolescents and parents regarding their treatment regimen and confusion due to changes in the regimen are barriers to self-management (Cox et al., 2014:130).

Having a framework for understanding illness and wellness is an element of chronic disease self-management (Swendeman et al., 2009:15). Persons who live with HIV may find monitoring their illness difficult since this is usually done by healthcare providers by means of blood tests such as CD4 cell counts and viral loads (Swendeman et al., 2009:15). From the qualitative data, it was evident that few adolescents were aware of what their CD4 count or viral load is or should be. Barnes et al. (2013:314) similarly found in a study on African American youth, that only 29.5% of adolescents knew their CD4 count or viral load. Knowledge about these biomarkers are therefore very unlikely to guide adolescents' decisions about taking treatment or risk behaviours. However, some adolescents seemed to know the signs and symptoms of being in ill health (health decline) and mentioned that these symptoms would alert them when they had not been taking their treatment. One adolescent mentioned that when he does not use a condom, he relies on the fact that his viral load is suppressed, and that when it is low, he can do anything he wants. He specifically referred to the risk of transmitting the virus to his partner, because he went on to explain that if he does not trust the

girl he will use a condom – perhaps meaning that if he was unsure whether she may infect him with a disease, he will use a condom.

Most adolescents did not monitor their own health and illness and relied on healthcare workers to inform them whether they were doing well or not. Karlson et al. (2008:567) found successful control of blood glucose led to increased motivation amongst adolescents who live with diabetes. I did not observe that an undetectable viral load was a motivator towards self-management in the present study. This may be because the adolescents did not know their viral load and non-adherence behaviour is not immediately associated with a high viral load since it is monitored annually.

Knowledge of prevention of HIV transmission and lifestyle behaviours that are healthy is important (Swendeman et al., 2009:15; Sattoe et al., 2015:709) for ensuring the performance of health promotion activities (Schulman-Green et al., 2012:139). The healthcare workers in this study insisted that adolescents had poor knowledge, although some older adolescents reported awareness of risk behaviours.

Swendeman et al. (2009:15) listed accessing appropriate treatments and services as a self-management element. Knowledge of navigating the healthcare system, such as how to contact a healthcare provider when needed, obtaining information about HIV and attending clinic or hospital appointments, is essential (Sattoe et al., 2015:709). The adolescents in this study only made use of the ART clinic to access treatment and rarely reported accessing other services, except when they were referred. Due to the structure of services, they may not see the same healthcare provider at a subsequent clinic/hospital visit, but they had a general idea of which healthcare providers treated them. Adolescents reported that they asked the healthcare providers if they had questions about their illness. Based on healthcare worker and adolescent accounts, adolescents were specifically interested to ask questions about relationships and sex. According to the healthcare workers, adolescents sometimes engaged with them, asked questions and volunteered information, while at other times they were quiet and withdrawn. Some preferred to ask questions in the privacy of the consultation room, while others were comfortable speaking in the support group. Knowledge about transfer to adult care was limited since in the context of this study, the adolescents preferred to stay in the adolescent groups due to the connections and friendships they had formed there. Only one healthcare worker mentioned that the adolescents were prepared to some extent for transfer to adult care. Healthcare workers were reluctant to transfer adolescents to adult care, since they reported that adolescents sometimes defaulted treatment after referral since they were not used to the way adult services were organised. There is therefore a need to better prepare adolescents for transfer to adult care and to support them during the transfer process. Higher self-efficacy and independence during hospital visits and consultations are associated with

being ready to transfer to adult care. Adolescents who report more discussions about transfer may be more positively inclined towards the transition (Van Staa, 2012:156).

Gaining knowledge and understanding seems to be a process that is facilitated through interactions with caregivers, healthcare workers and educators. In the light of IP it can also be said that social "disclosive" spaces that facilitate shared meanings are influenced by how the caregivers, healthcare workers and adolescents engage with each other. Inadequate knowledge and communication by caregivers and educators may lead to a lack of knowledge and understanding by the adolescent. This process is influenced by the adolescents' maturity, ability and readiness to engage or understand and should be reinforced continuously by both caregivers and healthcare workers, since disease specific knowledge can only be enforced when there is an awareness of illness. On the other hand, caregivers may be uncomfortable to share their knowledge due to the sensitivity of the issue. They may try to protect the adolescents for as long as possible by refraining from full disclosure or treat disclosure as a once-off event, thereby delaying the process of gradual knowledge acquisition. Reasons for non-disclosure of caregivers to perinatally-infected adolescents reported in the literature include the perceived inability of the child to understand, fear of negative emotional reactions, blaming the parent and fear that the child may disclose to others (Brown et al., 2011:1053; Abebe & Teferra, 2012:1097).

Adolescents with knowledgeable caregivers and who are exposed to regular discussions about HIV at home and at the healthcare facility may have more understanding. Similar findings were reported in a study assessing disease-specific knowledge among African American youth (Barnes et al., 2013:314). The study identified being behaviourally infected, providing discussions about CD4 cell count and viral load, having heard about or discussed resistance with one's provider and knowing one's CD4 count or viral load, was associated with higher HIV knowledge. Jena (2014:72) found that tailored age-specific services focused on the needs of perinatally-infected adolescents promoted their understanding and management of their illness.

5.2.1.2 Believing and valuing

Enhancing beliefs such as self-efficacy, outcome expectancy and goal congruence has been described by Ryan and Sawin (2009) as self-management processes. Schulman-Green (2012:137) also emphasises the emotional and existential challenges of living with a chronic illness such as reconciling emotions and deriving meaning from experience. Beliefs, including self-efficacy, an internal locus of control and confidence that treatment is working are associated with better self-management (Modi et al., 2012:474).

In this study, adolescents, caregivers and healthcare workers all agreed that it is important for an adolescent to know that they have a future and that they can engage in normal social activities. A belief that there is a future for a person living with HIV if they take their treatment, may be an important motivator to adhere to treatment plans and engage socially (Cluver et al., 2015:S57). Caregivers and healthcare workers tried to motivate adolescents to integrate their treatment and hospital visits into their normal routines, thereby normalising these behaviours. Yet, for many adolescents, taking treatment was a daily reminder of being different. Some adolescents accepted that they have HIV and the chronic nature thereof, while others struggled to accept their diagnosis. HIV affected the way adolescents viewed themselves. They wanted to be normal and not different from their peers. Petersen, Bhana, Myeza, Alicea and Johns, et al. (2010:973) also found that HIV-positive adolescents in South Africa experienced identify difficulties. Some adolescents experienced emotions such as anger or sadness and questioned why it happened to them. Feelings of anxiousness or nervousness and depression were prevalent amongst adolescents with HIV in Zambia (Mburu, et al., 2014:1) and were found to be barriers to self-management amongst adolescents with diabetes (Cox et al., 2014:130). Emotions such as depression can influence an adolescent's SM through decreased motivation for SM or the inability to pay attention or to concentrate (Modi et al., 2012:478).

Taking ownership and completing health tasks requires developing confidence and self-efficacy (Schulman-Green et al., 2012:139). Most of the adolescents in this study were confident about taking care of their own health and had dreams for the future. A sense of being in control of one's situation and one's health is also imperative. An exemplar identified was that adolescents and caregivers had the belief that they can control their illness through taking their treatment, and that in doing this, others will not know that they are infected with HIV. Although adolescents may not feel that they had control over their HIV-positive status, they demonstrated some self-efficacy in managing the illness.

Beliefs and values are also situated in the family and social context. The parent-child dyad involves reciprocal processes in which caregiver functioning impacts on adolescent functioning (Modi et al., 2012:474). Parental or caregiver beliefs about HIV are likely to be transferred to children and adolescents. Many adolescents in this study mentioned that their mothers were role models and helped them to accept their diagnosis.

In a study on self-management by adolescent patients with diabetes, Cox et al. (2014:133) found that denial of their chronic illness (that is, believing that nothing bad will happen if they do not take their treatment or trying to forget that they have an illness) and its consequences was reported by parents (but not by adolescents) as a barrier to self-management. Although many adolescents in the present study seemed to be aware of the consequences of not taking

their treatment, this knowledge did not seem to be a major determinant of their behaviour and other factors such as competing priorities or goal incongruence seemed to influence their behaviour. Awareness of the consequences of not taking treatment seemed to vary between individuals and changed over time. Some adolescents reported very drastic consequences (illness and death), while others reported that there was a time when they did not see the need for taking treatment since they were healthy.

In the context of the present study, various religious beliefs were mentioned by participants of which the dominant ones were Christianity and believing in ancestors. People's faith or spirituality may give them hope, help them manage emotions and facilitate the process of deriving meaning from their experience (Webel et al., 2012:17; Sattoe et al., 2015:709; Schulman-Green et al., 2012:137). Some adolescents in this study adopted belief systems from their community or family, while others seemed to be in the process of clarifying their own beliefs and values. Parents or caregivers were more likely to have spiritual beliefs such as that God will heal their children, where adolescents were more likely to hope that there will be a scientific cure for HIV or that the human race will evolve to adapt to the virus. Schulman-Green et al. (2012:137) also acknowledged the emotional challenges of living with a chronic illness and that people may derive meaning in different ways.

5.2.1.3 Self-regulation

Since self-regulation encompasses skills such as decision-making, problem solving, self-monitoring and goal-setting, it may be more difficult for adolescents to master. Although it is likely to improve with age, these skills may have to be taught and it cannot be assumed that the adolescent will automatically acquire the skill with maturity. As adolescents mature, other factors may also affect their ability to self-regulate. Goal-setting, decision-making, problem solving and planning is part of taking ownership of one's health needs (Schulman-Green, 2012:139).

Some healthcare workers acknowledged the challenges adolescents have with anticipating the consequences of their behaviour and felt that adolescents needed a lot of support with self-regulation processes and behaviours. Recognising and managing body responses, managing/taking medications and managing hospital/clinic appointments are important self-management tasks (Schulman-Green et al., 2012:139; Swendeman et al., 2009:15; Modi et al., 2012:476; Sattoe et al., 2015:709). Although adolescents in this study appeared to be in good health, they were aware that they should report ill health. Adolescents knew what type of symptoms to report to the doctor or nurse and some caregivers encouraged them to report these symptoms on their own. An exemplar identified was that most adolescents were not aware of how they are doing on their treatment (as monitored by their CD4 count and viral load) and did not actively engage or ask healthcare providers about their progress. They

appeared to rely on the healthcare workers to tell them if they are doing well or not. Participation in decision-making was very difficult to determine. It seemed as if some adolescents asked questions about their health while others were quiet.

The ability of an adolescent to manage daily activities and make decisions have been described by Karlson et al. (2008:565) as self-determination and is linked to factual and experiential knowledge. The most important daily activity of adolescents who live with HIV is taking treatment as prescribed. In this study, some adolescents reported taking treatment on their own and others only when being told or reminded. Some adolescents reported how they planned or failed to plan to take their treatment when they were not at home. There were instances where an adolescent would deliberately decide not to take treatment that was likely caused by some form of goal-incongruence, for example, being socially acceptable vs taking treatment at a certain time. Adolescents felt that taking treatment is not acceptable when amongst friends and did not want their friends questioning them about the treatment. Cox et al. (2014:130) also reports that refusal to give up time with friends to take care of the illness was a self-management barrier amongst adolescents who live with diabetes. Although some adolescents in the present study narrated that they did not take their treatment when going to a party, a few reported that their friends reminded them to take treatment. Others mentioned that they sometimes became tired of taking treatment but that they took their treatment even when they did not feel like it because they knew it was important, that it was '*their life'*.

More than one adolescent reported that they stopped taking ARVs for a period in the past or that they deliberately threw it away. These behaviours resulted in them not being virologically suppressed or in virological failure. When an adolescent is in virological failure due to non-adherence, healthcare workers advised that parental control is increased by way of directly observing them taking treatment and increase the frequency of clinic visits. On the other hand, when they were virologically suppressed with no adherence concerns it resulted in less frequent clinic visits and more freedom to manage the treatment on their own. Karlson et al. (2008:566) found that psychological maturity amongst adolescents with diabetes resulted in increased responsibility and freedom.

In this study, some adolescents mentioned that their parents reminded them to take their treatment. Young adolescents seemed to be monitored more closely while some older adolescents were expected to manage treatment on their own. Healthcare workers frequently mentioned that they cautioned caregivers against transferring complete responsibility for taking their treatment to the adolescent, while caregivers reported that it was more difficult to monitor treatment if the adolescent was older. Some caregivers were under the impression that the adolescent was taking their treatment when they were not. Treatment taking behaviours or adherence were difficult to monitor clinically since there were no immediate

effects on the health of an adolescent if they do not take their treatment and a viral load was only required annually. Karlson et al. (2008:562) found that the transition process towards autonomy in self-management amongst adolescents who live with diabetes was characterised by hovering between individual actions and the support of others. Adolescents required the freedom to make their own decisions, but still needed to retain the support of others. This "hovering" created an unclear responsibility with respect to self-management activities that in some instances lead to family conflicts such as the adolescent blaming the parent for not reminding him/her to take treatment. Cluver et al. (2015:57) found that full adherence was negatively associated with being older which may be related to the fact that the treatment taking behaviours of older adolescents are less strictly monitored. Maskew et al. (2016:1) similarly found that older adolescents were more likely to miss clinic visits. This may indicate the importance of teaching adolescents self-management skills before their transition into adulthood.

Self-monitoring occurred by remembering to take treatment and attend clinic appointments. Most of the adolescents in this study attended the clinic on their own. Another South African study conversely reports that 74.7% of adolescents were accompanied to the clinic. A larger percentage of adolescents who knew their HIV status attended the clinic alone compared to those not knowing their HIV status (Cluver et al., 2015:57). In the context of the present study, other factors, such as the clinic location and pharmacy rules also influenced whether adolescents attended the clinic alone. Older adolescents were more likely to attend appointments on their own.

Although adolescents had knowledge of healthy behaviours, very few adolescents reported engaging in healthy behaviours or planning to change their behaviours to promote their health. Some sexually active adolescents reported using condoms and contraception. Adolescents made decisions about HIV status disclosure and some narrated how they assessed whether they could safely disclose to someone. Others mentioned being pressurised by their caregivers not to disclose to anyone. Problem solving was not a skill that was very apparent. The only problem-solving example in the context of HIV self-management that was provided by the adolescents was how to determine whether it is safe to disclose one's HIV status to a friend or romantic partner. Cox et al. (2014:130) found that difficulty to plan and problem solve were barriers to self-management behaviours.

Schilling et al. (2009:233) in their self-report measure for self-management for Type 1 diabetes included several items related to goals. Goals were being independent, being in charge of treatment, to feel good, to be able to stay away overnight and to understand blood sugar levels/numbers. In the present study, adolescents had more general goals such as finishing school, studying further or having a family. Similar future plans and aspirations were reported

by Jena (2014:81) amongst HIV-infected adolescents in the Eastern Cape. Some adolescents in the present study mentioned that they wanted to be independent and live a normal life. Almost none of the adolescents had goals for their health, for example, to have a high CD4 count and an undetectable viral load. This may be because they were all generally healthy or did not understand the need for these goals. The largest percentage were also virologically suppressed and it may be that they are only referred for counselling that reinforces knowledge of these measures if they are not adherent/unsuppressed.

5.2.1.4 Coping

Coping with a chronic condition is part of self-management (Sattoe et al., 2015:708) and coping strategies are incorporated in many self-management education programs. Coping can also be part of self-regulation, but I grouped it in a separate theme. Coping with stigma, shame, discrimination, social rejection and strategically managing disclosure are predictable challenges of living with HIV (Swendeman et al., 2010:6). Adolescents and caregivers narrated how they coped with and managed stigma. In the examples provided, stigma was perceived and enacted. It included being able to cope when people in their family, community or children at school say hurtful things about people living with HIV. Generally, they coped by ignoring such comments or thinking about something else, indicating passive emotional regulation. Other adolescents coped by trying to avoid conversations about HIV (social withdrawal) or by participating in sports or doing other things such as listening to music (distraction). A few examples were provided of being rejected after disclosing their HIV status and/or being treated differently. Passive emotional-regulation was perceived to be the most helpful coping strategy in a sample of HIV-infected adolescents in the United States since they may lack control of stressors such as medication side-effects or stigma. Resignation was the most commonly used strategy to address adherence-related stressors and passive emotional-regulation was the most often used to manage disclosure related stressors (Orban, Stein, Koenig, Conner, Rexhouse, et al., 2010:424). In South Africa, a future orientation, HIV information and social support enabled HIV-positive adolescents to cope better with their illness (Petersen et al., 2010:970).

Adolescents reported feelings of anger and depression after finding out their HIV status and a few resorted to using alcohol or drugs to cope. If adolescents were disclosed to early (before the age of 10) and the information provided focused on the fact that it was not their mother's fault, they seemed to handle the news better. One adolescent specifically mentioned that she thinks it was easier for her to accept her status since her mother disclosed to her when she was still young by specifically relating a story of her father infecting her mother unknowingly. She also added that when you are younger you are less aware of stigma. Adolescents in Zambia described having feelings of anxiousness, depression and blaming themselves and

others after being disclosed to (Mburu, Hodgson, Kalibala, Haamuompa, Cataldo, Lownethal & Ross, 2014:1). Similar findings were reported in South Africa by Jena (2014:58). However, disclosure may create opportunities for access to adherence and psychological support (Mburu et al., 2014:1) and enable self-management (Jena, 2014:60).

Due to strained parental relationships and non-disclosure to friends, few adolescents could openly talk about their feelings. Participation in the adolescent group made adolescents feel that they could be themselves which is similar to findings reported by Jena (2014:71). However, healthcare providers mentioned that some adolescents did not participate or did not want to participate in the groups that may have been due to not accepting their status. Poor adjustment to the disease, its management and other life stressors can lead to ineffective self-management (Modi et al., 2012:478).

5.2.1.5 Communication and disclosure

Activating resources such as healthcare resources, psychological and social resources requires effective communication skills (Schulman-Green et al., 2012:139). In the present study, communication took place between adolescents and their peers, family members, caregivers, community members, teachers and healthcare workers. Some adolescents were more talkative and some more reserved which may be a personality trait or because they felt that they needed to build a relationship of trust with a person before they share personal information.

Communication with the medical team is a key self-management process described by Modi et al. (2012:477). Managing hospital appointments independently includes communicating with the healthcare provider (Van Staa, 2012:162). Adolescents seemed to share a fair amount of information about their health and sometimes their personal circumstances and situations with healthcare workers. Some adolescents mentioned that they would ask questions about their illness if there was anything they did not understand. Healthcare workers reported talking to adolescents about a range of topics including adherence, sexual behaviours and alcohol use. According to healthcare workers, adolescents who were at the clinic for longer and the older adolescents were more likely to share information. Cox et al. (2014:130) found that a lack of trust in healthcare workers were a barrier to self-management. None of the adolescents in the present study reported that they did not trust the healthcare workers, on the contrary some reported that they did trust the healthcare workers.

Most adolescents did not have open sharing relationships with their parents or caregivers. Some felt that they could not talk to their parents about HIV since it was uncomfortable and their parents did not have enough knowledge to answer their questions. One mother, who was also an HIV counsellor, mentioned that she spent a lot of time talking to and educating

her adolescent daughter about HIV as well as other adolescent issues and related that it requires effort on the part of the caregiver. Family interactions such as listening to the child's ideas about taking care of his/her illness and understanding how the child feels about having the illness can positively affect self-management (Cox et al., 2014:131).

The peer groups at the clinic facilitated discussions around sensitive topics. Adolescents in Zimbabwe learned information about living with an HIV-positive status and the meaning thereof from shared experiences among peers at the clinic (Kidia, Mupambireyi, Cluver, Ndhlovu, Borok & Ferrand, 2014:1). Some adolescents in the present study acknowledged that they never talked about HIV outside the hospital/clinic/peer group setting while others mentioned disclosing to close friends whom they trust. Few adolescents disclosed to sexual partners. The key barrier to communication and disclosure narrated by participants was a lack of trust. When asked to whom they would be willing to disclose, most said to a person they trusted. However, this trust was viewed differently with some adolescents saying that they will only disclose their status to a person they are in a relationship with if they had been partners for years or before they marry, while others felt that no one could be trusted. Some did trust people and disclosed to them and were disappointed, whereas, others had a positive experience. Jena (2014:62) similarly found that self-disclosure was related to a perceived lack of trust amongst adolescents interviewed in the Eastern Cape and Weintraub et al. (2017:129) also reported reluctance to disclose to sexual partners amongst adolescents in the United States.

In this study a few adolescents reported that school teachers knew their HIV status. Perceived support from school teachers were mixed, with some reporting that teachers were caring, while others felt that they were treated differently by them. Petersen et al. (2010:973) reported that HIV disclosure to school teachers increased academic support. This was however not evident in the present study.

5.2.1.6 Social facilitation

A key self-managing process is activating resources. Skills related to activating social resources include seeking support of family and friends, being proactive in limiting isolation and creating a community of peers with similar experiences. Community resources can be activated through seeking assistance within the community or utilising services such as transportation (Schulman-Green et al., 2012:139). Support from family is especially important in paediatric self-management (Modi et al., 2012:477).

Most adolescents seemed to be supported by their close family. In some cases, only the mother or caregiver knew about their status and not the rest of the family. Support lacked in some situations, for example, where caregivers had changed or where the caregiver had

problems with alcohol use. Since most adolescents' treatment regimens were not complex, the role of parents or caregivers were mostly to remind the adolescents to take their treatment. It also included support in dealing with stigma and other general life issues. One adolescent explained that the support and love of his family made him feel happy and healthy. According to Modi et al. (2012:478), parental involvement and family interaction supports illness management.

Healthcare workers and caregivers related that adherence problems amongst older adolescents are sometimes attributed to prioritising friends or other activities over treatment. Some caregivers explained that they have to continuously remind their adolescent to take treatment. Cox et al. (2014:133) found that adolescents who live with diabetes and their parents reported self-management barriers around peer and family interactions. This was ascribed to adolescents placing higher importance on peer interactions while attempting to separate from their parents and assert independence. Adolescents who live with diabetes reported that parental involvement, support and trust to make their own decisions helped them to progress towards self-management. Parents who nag their adolescents about their self-management behaviours seemed to decrease their motivation to prioritise these activities (Karlson et al., 2008:567).

In general, adolescents were happy with the services and healthcare workers at the clinic or hospital. Although they did not receive direct support from healthcare workers, the idea that they were accepted at the clinic or hospital seemed to be comforting and many mentioned that the clinic or hospital was the place where they could ask questions about HIV and where they learned about HIV. Some instances were mentioned of healthcare workers shouting, lacking respect or being too busy. One adolescent specifically felt that counsellors should be more understanding and communicate in a non-judgemental way. Cox et al. (2014:130) found that a lack of trust in healthcare providers, being treated as a child, healthcare workers being rushed or too busy, and healthcare workers' lack of understanding on how the regimen impacts on the daily activities of the adolescent, were barriers to self-management. A perception that healthcare workers are friendly, approachable and good at explaining things were facilitators to self-management.

Many adolescents enjoyed the peer groups or clubs. They liked spending time with other adolescents in the same situation since few disclosed to friends due to fear of stigma. Kidia et al. (2014:1) found that adolescents valued peer support and that this reduced the burden of psychological care on caregivers and healthcare workers. Conversely, Modi et al. (2012:479), found that adolescents may, however, not utilise peer support to avoid being identified as being ill. Adolescents in the present study did not appear to be worried that they will be identified through attendance of the group. This may be because the groups at the

primary healthcare site was held in the afternoon in a room that was not close to the HIV services. The group at the hospital was also held in a room that was not in the same area as the infectious diseases clinic. One caregiver mentioned that her son stopped attending another HIV support group because his friends started to ask questions. In contrast, in the study by Karlson et al. (2008:568), adolescents with diabetes reported feeling safe and secure knowing that their friends knew that they had diabetes and expressed being able to forget about their illness for a while in their company. In the present study, only a few adolescents disclosed their status to close friends. Most preferred that their friends did not know, perhaps because it made them feel normal and they did not want to be labelled by their HIV status. Engaging with friends who knew about their status and those who did not know, both seemed to have benefits. One adolescent mentioned forgetting about his illness when playing with his friends, since he was able to enjoy the company of his friends without them being aware of his status. Another adolescent mentioned that he was very popular at school and if people find out about his HIV status that may change. Some adolescents communicated via cell phone or WhatsApp. Online communities and social networking may have some benefits to decrease isolation (Modi et al., 2012:479). However, in the present study it was noted that not all adolescents had cell phones and that cell phones were often stolen or lost.

Apart from going to school, some adolescents were also involved in community activities or sports that especially healthcare workers and caregivers thought was good as it kept them busy with other things and helped them to socialise with peers. Participation in community events and youth groups may positively influence SM (Modi et al., 2012:478). However, facilities for community activities were reportedly not easily available or accessible. Those in foster care seemed to be aware of social workers and where to go if they had problems with their foster parents.

5.2.2 Caregiver challenges

This theme had three sub-themes: knowledge and skills; socioeconomic difficulties; and responsibilities.

5.2.2.1 Knowledge and skills

Adolescents, caregivers and healthcare workers felt that caregivers' knowledge was inadequate to engage in meaningful conversations about HIV with their adolescents. They also lacked skills to disclose, communicate and manage adolescent behaviours. Caregivers often lacked support from family. Modi et al. (2012:478) found that higher caregiver health literacy and perceived social support promotes SM. Some caregivers reported asking assistance from the clinic's counsellors to help them disclose their adolescent's HIV status to them. Similar findings have been reported by Abebe and Teferra (2012:1097) who conducted

a study in Ethiopia. Although healthcare workers have been trained to encourage parents to disclose in the home environment, adolescents in Zimbabwe favoured disclosure at clinics in presence of the healthcare workers since it gave them access to accurate information (Kidia et al., 2014:1). A study in South Africa found that disclosure to children and adolescents is challenging for healthcare workers and brings about many ethical dilemmas since they are not sure if they can disclose to adolescents, especially if the caregiver was not present or did not seem to intend on doing so (Watermeyer, 2015:590).

5.2.2.2 Socioeconomic difficulties

Although none of the participants interviewed seemed to have serious socioeconomic difficulties, many reported a lack of transport money or money to buy the things adolescents needed or wanted. Some caregivers felt that there was inadequate support from the government to care for HIV-positive children and adolescents who may have special needs, for example, extra classes for certain school subjects. According to Petersen et al. (2010:970) and Kidman and Hayman (2016:142), caregivers are struggling to support children who live with HIV. They advocate for policies to address the needs of HIV-affected caregivers. Although South Africa is listed as a country with a robust package of economic provisions (Kidman & Hayman, 2016:148), the qualitative evidence from this study shows that there are still unmet needs among caregivers who care for HIV-positive adolescents. A qualitative study conducted in Cape Town, South Africa, amongst HIV-infected adolescents, also found that the basic material needs of adolescents were unmet (Li, Jaspan, O'Brien, Rabie, Cotton, & Nattrass, 2010:753).

5.2.2.3 Responsibilities

Family caregivers are very involved in caring for children living with HIV (Biru, Lundqvist, Molla, Jerene & Hallström, 2015:282). Caregivers in the present study reported that caring for an HIV-positive child was more intense than caring for an HIV-negative child. Some caregivers also had HIV and attended clinic appointments with the adolescent and then had to attend a separate clinic for their own appointments. These caregivers had to manage emotions such as guilt or the relational repercussions of lying to the adolescent about their HIV diagnosis. Supervising adolescents taking their treatment was challenging for some caregivers who worked long hours. Biru et al. (2015:282) and Hejoaka (2009:869) found that caregivers were very committed to caring for children living with HIV. However, caregivers, especially mothers, often experienced extensive worry, had caring burdens and inadequate family and social networks. Many caregivers found meaning and stayed positive through believing in God and relied on the support of healthcare workers (Biru et al., 2015:282). Some caregivers in the present study reported trusting God that the adolescent will be cured or mentioned that their beliefs gives them hope. Certain adolescents also reported being prayed for to be cured. This

may be because the religious background of caregivers influences the way they view health and illness or because they use religion as a coping strategy.

Healthcare workers reported that some older caregivers such as grandmothers struggled with their own health and had no support. According to Modi et al. (2012:478), psychological symptoms such as anxiety, caregiver burden and stress can negatively influence SM. There were no support groups for caregivers at the study sites at the time of the study. Interventions to support caregivers is needed throughout the continuum of care for HIV-positive children and adolescents (Biru et al., 2015:282). The use of parent-to-parent support groups or community health workers could also be explored further (Kisesa & Chamla, 2016:S4).

5.2.3 Putting the spotlight on HIV

The sub-themes for this theme are stigma, fears of rejection and telling lies.

5.2.3.1 Stigma

Participants described stigma as carrying a burden or secret with them that needs to be kept hidden. Most participants worked very hard to make sure that their status remains confidential due to the fear of stigma and discrimination should others find out. Perceived and enacted stigma is still rife in families, schools and communities. A lack of accurate information of HIV and general indifference were identified as the main reasons for persistent stigma. Within the community and in schools people used colloquial labels for those they suspected were HIV-positive.

Stigma was also promoted in healthcare facilities through the way the healthcare facility and care were organised, specifically by separating HIV services from other general care. In some cases, this perceived and enacted stigma prevented adolescents who live with HIV and their caregivers to access health services and obtain adequate support to manage their illness. A qualitative study conducted in Kenya found that while knowledge about HIV and access to treatment is increasing, inaccurate and negative views still persists in communities. The impact of stigma included non-adherence, nondisclosure of status and increased mental health problems (McHenry, Nyandiko, Scanion, Fischer, McAteer, et al., 2016:215). Comfort, Atrio, Watnick, Gutierrez, Abadi, et al. (2016:421) found that perinatally HIV-infected adolescents in the United States experienced intense stigma within sexual relationships and in their communities. They concluded that HIV stigma causes a lack of health agency, education and access to resources.

In Kenya, approximately one-third of adolescents with HIV reported low emotional and informational support, and the majority reported HIV-related stigma linked to disclosure and public attitudes. There was also a strong negative correlation between the degree of HIV-

related stigma and social support (Levy, Ong'wen, Lyon, Cohen, D'Angelo, et al., 2016:S82), indicating that social support may negate the negative effects of stigma.

A South African study conducted in the Eastern Cape found that adolescents anticipated stigma from the community since HIV is seen as punishment from God or their ancestors (Pantelic, Boyes, Cluver & Thabeng, 2016:1). They also found that enacted HIV stigma was associated with higher AIDS symptomatology and anticipated stigma with higher levels of depression. Participants of the present study provided examples of internalised stigma such as shame, guilt and suicidality. Although some mentioned that they questioned whether God allowed them to have the illness or viewed it as a curse, they did not see it as a punishment from God.

5.2.3.2 Fears of rejection

Many adolescents feared that they might be treated differently and rejected once someone found out about their HIV status. Adolescents and healthcare workers mentioned instances where friends or family rejected adolescents because of their HIV status. Pantelic et al. (2016:11) found that 2.5% of adolescents (of a sample of 721) living with HIV in the Eastern Cape, South Africa reported being teased because of their HIV; 2.1% lost friends after disclosing to them they had HIV; 3.2% stopped spending time with some children because of their reactions to their HIV status; and 19.9% reported that they have been hurt by how people reacted when they found out that they had HIV. Adolescents living with HIV in Malawi reported being bullied for taking medication (Kim et al., 2015:264).

5.2.3.3 Telling lies

Many adolescents made a lot of effort to keep their HIV status a secret. This resulted in them telling lies about attending clinic/hospital appointments or about taking treatment. Some even boasted about how well they could tell lies about why they have to attend clinic appointments and one adolescent girl reported that she even had to lie to her sister. Pantelic et al. (2016:11) found that 77.8% of adolescents living with HIV in the Eastern Cape reported to being very careful who they tell about their HIV status. Adolescents and caregivers in Kenya described hiding their medications, taking it in secret and attending a clinic that allowed them to keep their HIV status a secret from the community (McHenry et al., 2016:5).

It is therefore evident that in the current study context and in the national, African and international context, perceived, enacted and internalised stigma is still continuing and may negatively affect the self-management of adolescents living with HIV.

5.2.4 Healthcare system

Sub-themes related to the healthcare system included adolescent preferences, clinic/hospital functioning and healthcare worker attitudes.

5.2.4.1 Adolescent preferences

Adolescents primarily enjoyed attending the clinic. They preferred to be treated with respect and appreciated confidentiality. Short waiting times and a well-organised service seemed to enhance their experience of the clinic. One adolescent recommended more flexible clinic times or using a private doctor to avoid long waiting times at the clinic and so that he does not miss important school activities while another mentioned not wanting to attend the clinic during holidays. Healthcare workers reported that certain adolescents had preferences for whom they wanted to be seen by, although only one adolescent reported disliking a particular provider that led to her attending a different clinic. Her mother explained that the particular doctor addressed the mother strongly in front of the adolescent about adherence concerns where after she did not want to attend the clinic anymore.

Toska, Cluver, Boyes, Isaacsohn, Hodes and Sherr (2016:4) investigated, amongst other factors, the effect of adolescent-sensitive clinic care on sexual behaviour of adolescents who live with HIV. They measured whether a clinic was adolescent-sensitive through asking adolescents if they felt disrespected or were scolded. Adolescent-sensitive care from healthcare providers were associated with lower rates of unprotected sex (Toska et al., 2016:10). HIV-infected adolescents in Zambia appreciated services that were welcoming and provided information tailored to their needs (Hodgson, Ross, Haamujompa, C & Gitau-Mburu, 2012:1204). Poor clinic care that is not congruent with the expectations of adolescents may therefore have a negative effect on adolescent health outcomes.

5.2.4.2 Clinic/hospital functioning

The healthcare environment (structures and services) can influence healthcare workers' ability to render services, their work-related satisfaction and adolescents' perception of care quality (Modi et al., 2012:479). It was observed in this study that a lack of dedicated staff, organisation and continuity of care negatively influenced the experiences of adolescents and their willingness to attend the clinic. A South African study in Johannesburg found that the most frequently reported perceived barriers to care for adolescents accessing ART were related to clinic visits and included time and cost involved in getting to the clinic and the time spent at the clinic (Maskew et al., 2016:7).

Adolescents in the present study enjoyed attending support groups or clubs. However, these support groups require a person with a special interest in adolescents to facilitate discussions and ensure that the correct information is transferred. Obtaining such a person and ensuring

continuity was challenging at both study sites. Support groups may also not be equally important for older and younger adolescents. Maskew et al. (2016:5) found that younger adolescents were more impacted by lack of peer support and counselling compared to older adolescents. Older adolescents' adherence to clinic visits were more affected by the perceived lack of sexual health services. This was not observed in the current study as both younger and older adolescents expressed that they enjoyed support groups. Older adolescents did not want to be transferred to adult services. Healthcare workers reported that sexual health services were incorporated in the care and those female adolescents who asked for contraception were provided with this at the same clinic visit.

5.2.4.3 Health care worker attitudes

Good communication between healthcare staff, adolescents and family members are essential for collaboration (Modi et al., 2012:479). Healthcare workers, caregivers and adolescents may have different expectations of what is appropriate to discuss. In the present study, some adolescents seemed comfortable to discuss private information, while others were reluctant.

Healthcare workers may not always address adolescents directly. I observed that when a caregiver attended an appointment with an adolescent, the healthcare worker more likely addressed the caregiver than the adolescent. The provider-patient fit may also affect how adolescents manage their chronic illness (Modi et al., 2012:479). Some adolescents may prefer certain healthcare workers above others and may interact better with them as reported by healthcare workers in this study.

It was evident from the current study that healthcare workers needed skills to communicate with adolescents on their level. Healthcare workers were sometimes forced to work with adolescents since there were nobody else willing to do so. More than one healthcare worker reported that it is important that the person who works with the adolescents have a passion to work with this age group. One adolescent reported that the counselling style of counsellors was not open and encouraging. Kisesa and Chamla (2016:S1) commented that improved clinical and social support is critical in reducing AIDS-related deaths amongst adolescents. This requires adapting adherence support and service delivery models that encourages meaningful adolescent participation (Kisesa & Chamla, 2016:S4).

5.2.5 Factors influencing self-management

Factors that influence self-management include disease and treatment characteristics; individual differences; family context; healthcare system structure and functioning; and community influences. Demographic factors (such as SES and culture), clinical factors (such

as comorbidities and complexity of the treatment regimen), and system factors (such as the quality of relationships and communication with providers) can affect SM (Schulman-Green et al., 2012:141).

5.2.5.1 Disease and treatment characteristics

Adolescents in this study were primarily perinatally infected and most were doing well on treatment. Perinatally-infected children are more likely to be adherent to treatment since they have been on treatment for longer compared to behaviourally-infected adolescents (Maskew et al., 2016:9). Many adolescents found taking treatment difficult and reported problems with swallowing tablets. A few also reported minor side-effects. Those adolescents who had to take twice daily doses reported difficulty in taking the morning dose. Cox et al. (2014:130) found that the barriers to self-management for adolescents who live with diabetes are the side effects of the treatment, that the treatment regimen takes a lot of time and work and causes changes in the body of the adolescent. No adolescents in the present study reported any changes in their body caused by the treatment. This may be due to the phasing out of the drug stavudine that was responsible for causing lipodystrophy. Maskew et al. (2016:4) reported that adolescents who had problems with taking medications and became tired of taking medication, were more likely to miss clinic visits.

5.2.5.2 Individual differences

Healthcare workers described various differences in the emotional, physical and social development of adolescents who live with HIV. In many cases, there was no apparent reason why some developed well and had almost no health or behavioural complications and others had delayed development and behavioural or other complications. Amongst these differences, there was also normal adolescent behaviour, forgetfulness and other behavioural and emotional problems. Psychological, behavioural and emotional problems influence self-management (Modi et al., 2012:476).

Healthcare workers and caregivers reported that adherence became a problem as children enter adolescence. Modi et al. (2012:476) reports that self-management deteriorates from childhood through adolescence. Self-management is also compromised when the expected SM processes or behaviours required do not match the intellectual capacity or maturity level of the adolescent (for example, very complex treatment regimens). Maskew et al. (2016:3) found that older adolescents (15-20 years) attending ART clinics in Johannesburg were more likely to miss a clinic visit compared to younger adolescents (12-14 years).

Individual differences that relate to adolescent developmental tasks were also observed. Adolescents in this study experienced various challenges such as dealing with an HIV diagnosis that makes them feel different, HIV stigma and having to adhere to treatment. These

challenges may affect developmental tasks such as identify formation, the development of autonomy and meaningful peer relationships (Kang, Mellins, Ng, Robinson & Abrams, 2008:228). Although the need to be normal was an exemplar identified amongst adolescents in this study, they appeared to be at different levels of accepting and integrating their diagnosis into their identity. Some still did not want to hear discussions about HIV and preferred forgetting about their diagnosis, while others iterated that being HIV-positive did not change their person. The process of accepting one's HIV status appeared to take time and depending on the support received, may worsen identity conflict. In this study, role models, such as HIV-positive mothers or family members who were doing well on treatment and living 'normal lives' assisted adolescents to accept their HIV status. Enacted and internalised HIV stigma, as identified in the present study, may hinder positive identity development and how adolescents view their future role in society (Kang et al., 2008:232). Identity conflict and not accepting one's HIV status may further lead to emotional and behavioural problems, including non-adherence to treatment.

In this study, adolescents managed their illness at various levels of autonomy. Some independently took their treatment, attended clinic visits and made decisions about HIV disclosure while others needed to be, or even preferred to be, reminded of treatment and clinic visits. In some cases, caregivers strictly monitored treatment and reported to be very protective over their adolescent, while in other cases the responsibility of taking treatment was transferred to the adolescent. Healthcare workers doubted whether adolescents had the skills for self-management and was reluctant to transfer them to adult services since they may default in a setting where they do not receive special attention. Kang et al. (2008:230) state that autonomy development in adolescents with HIV may be complicated due to healthcare workers and caregivers treating adolescents "with kid gloves", affording them special attention and caregivers' finding it difficult to discern how much autonomy to give adolescents. Although HIV-positive adolescents may have more autonomy in other areas, their ability to independently manage their medication may be limited due to a lack of being future-orientated, neurodevelopmental delay or behavioural challenges (Kang et al., 2008:230).

Adolescence is a period where a young person become more dependent on peers for support and affirmation. However, this process may be complex for HIV-positive adolescents due to HIV stigma. Adolescents in the present study had relationships with other HIV-positive adolescents at the clinic and with friends who may or may not know their status. Family members such as cousins or siblings were also a source of support for some. Adolescents were generally very careful about whom they disclosed their status to and therefore found attending the support group at the clinic comforting since it was a place where they could relate to other adolescents with the same illness. Some adolescents avoided close friendships due to the fear that they may eventually be rejected once the person learn about their HIV

status. Jena (2014:66) reported that HIV-positive adolescents deliberately isolated themselves from peers since fear of disclosure overshadowed the need for friendships. Navigating peer relationships may be more challenging for HIV-positive adolescents who start having deeper friendships and romantic interests (Kang et al., 2008:231).

5.2.5.3 Family context

Most of the caregivers in the study were single mothers, grandmothers or aunts. These caregivers reported several challenges, especially those related to their socio-economic circumstances. Single parenthood has been associated with poorer SM since these families may have less support and fewer resources (Modi et al., 2012:478). Thirty-two percent of 12 to 20 year old adolescents on ART in Johannesburg, South Africa, reported an elderly caregiver as a potential barrier to care. This barrier was more frequently reported by older adolescents and may reflect increased responsibility of older adolescents in caring for elderly family members (Maskew et al., 2016:1). Adolescents with their mother as primary caregiver were less likely to miss clinic visits (Maskew et al., 2016:3).

The socioeconomic status (SES) of a family is associated with health disparities (Modi et al., 2012:478) and although healthcare is provided free of charge in the public sector of South Africa for those who cannot afford healthcare, most of the adolescents came from low income families. Most of the participants in this study were Black, followed by Coloured participants. Diseases such as HIV are still disproportionately affecting a very high proportion of Black and Coloured people due to historical and SES disadvantages. Thirty-two percent of adolescents in Johannesburg listed high transport cost to attend clinic visits as a potential barrier to care. Adolescents who thought having a caregiver with financial difficulties was a barrier to care were more likely to miss a clinic visit (Maskew et al., 2016:3). Petersen et al. (2010:970) reported that financial and social support was key aspects in fostering a supportive environment for adolescents living with HIV in South Africa.

There was a general lack of communication between caregivers and adolescents and almost none of the adolescents reported talking to their caregivers about HIV. Family communication is key in effectively negotiating disease management tasks and problem-solving. Caregiver involvement and monitoring, family cohesion, support, efficacy and flexibility are associated with effective SM while increased family conflict hinders SM (Modi et al., 2012:478). A perception that the family does not understand what it is like to live with a chronic illness and a lack of support were identified as possible barriers to self-management amongst adolescents who live with diabetes. An understanding family and having someone to talk to were seen as facilitating factors (Cox et al., 2014:130). In the present study, it was especially difficult for adolescents if they were the only HIV-positive child in the family. However, some adolescents narrated that they could talk to and received support from siblings or cousins. Another

possible barrier to SM was the angry response of the caregiver towards the adolescent when the adolescent did not take their medication. One male adolescent in the present study narrated that conversations with his parents about his non-adherence made him very emotional, while another adolescent felt it was appropriate for his grandmother to reprimand him.

5.2.5.4 Health system functioning

The way the healthcare system currently functions and the healthcare provider attitudes may determine whether adolescents attend appointments that in turn may affect their adherence. In Johannesburg, 31% of adolescents saw long queues at the clinic as a potential barrier to care (Maskew et al., 2016:3). Adolescents who felt that unfriendly healthcare workers were a barrier to care were more likely to miss clinic visits. Further, adolescents with unsuppressed VLs were more likely to perceive inconvenient clinic operating hours and long queues as barriers to care (Maskew et al., 2016:4).

Innovations to support adolescents who live with HIV is needed and ART clinics need to be made adolescent friendly (Kisesa & Dick, 2016:S4). Alongside adolescent-tailored support models, the use of short message services on mobile phones for medical appointments or treatment collection could improve adherence (Kisesa & Dick, 2016:S4). However, in the context of the present study, adolescents were likely to lose or sell mobile phones provided to them. Given the high crime rate in the community, it is also probable that a mobile phone will be stolen, making such an intervention less feasible. The availability of point-of-care VL measurements could lead to adolescents being more aware of their VL (Kisesa & Dick, 2016:S4).

Adolescents had to travel some distance to attend the clinic. Even some of the adolescents who attended the community clinic had to make use of public transport since they did not attend their nearest clinic for fear of being recognised. Although healthcare workers reported that adolescents were sometimes late due to the time it took to travel, none of the participants stated that transport problems prevented them from attending the clinic. One adolescent mentioned that if required, his mother borrowed money for transport in order for them to attend the clinic. In Johannesburg, 61% of adolescents agreed that travelling distance was a potential barrier to care. Thirty-three percent of adolescents in Johannesburg felt that being noticed by friends or other school children when attending the clinic was a barrier to care (Maskew et al., 2016:3).

5.2.5.5 Community influences

Stigma in families, schools and the community influenced the SM behaviour of adolescents and caregivers in this study. Illness-related stigma in schools and communities can impede

SM within these contexts. Limited schoolteacher knowledge and training as well as children's negative perceptions about support from teachers have been associated with poor health outcomes (Modi et al., 2012:478). The perceived barrier to care that that clinic visits will be noticed by friends was associated with a 70% increased risk of subsequently missing a clinic visit in a study conducted by Maskew et al. (2016:10).

Community stressors such as crime, violence, gangsters and bullying, as reported by participants, in this study may adversely affect SM. Similar findings have been reported in another study conducted in Cape Town, South Africa (Li et al., 2010:753). Adolescents mentioned that bullying at school was very common, but none related instances of being teased or bullied because of their HIV status although they feared that they would be bullied if their status became known. Children who live with a chronic illness are more likely to be bullied (Van Staa, 2012:17).

5.3 ITEM GENERATION

I linked the themes and sub-themes related to self-management processes and behaviours identified in phase one to the theoretical framework and other literature where applicable. This process went through a series of rounds where I went back and forth between the literature and the data from phase one, taking care to include the participants' views. The study supervisors were also consulted in the process. This occurred until saturation of each component of self-management was reached. Self-management processes were well described based on the literature and contextualised with the participants' views. Once the sub-themes were linked to the data, the researcher identified key statements that described each self-management process. These statements (items) were based on participants' words as far as possible.

I included items across the sub-themes identified in the first phase of the study and ensured that items were consistent with the domain definition and that they were as clear as possible (not long, vague or complex). Double-barrelled questions were excluded and examples were used only to illustrate the meaning of an item where necessary. Although written on a sixth grade literacy level, the use of slang was avoided and care was taken to ensure general applicability, i.e., not too narrow focused (PROMIS, 2013:17). In order to assess current self-management and minimise recall bias, the questions were phrased in the present tense. Participants were asked to answer questions based on how they felt or on what they knew currently on the day of completing the questionnaire.

Items were written in a table that links theory extracted from the literature (etic viewpoint, deductive logic) with the information provided by participants (emic viewpoints, indicative

logic) (Onwuegbuzie et al., 2010:63). A list of 55 items were identified through the process of item generation. The list of items is depicted in Table 5.1.

Table 5.1 Items generated in phase two

ITEMS		LITERATURE REFERENCES	SUB-THEME	PARTICIPANT QUOTATIONS
Domain 1: Knowing and believing *(may include self-efficacy, outcome expectancy and goal congruence)* Ryan & Sawin, 2009; Schulman-Green et al., 2012 (SCALE: Yes, certainly; Yes, probably; No, probably not; No, certainly not – Van Staa, 2012)				
1a KNOWING AND UNDERSTANDING				
1	I can describe the future consequences or concerns of my illness (HIV).	Barnes et al, 2013; Sattoe et al., 2015; Van Staa, 2012; Buran et al., 2006	Knowing and Understanding - HIV	*'Yes, what it is and to know that she accepts what she is living with and what the consequences are.'* [Caregiver 3, Mother]
2	I know how to prevent complications from my illness.	Barnes et al, 2013; Sattoe et al., 2015; Van Staa, 2012; Buran et al., 2006	Knowing and Understanding - HIV	'*Like some of them might have been disclosed to, but they don't really understand the implications of HIV, like long term.'* [Healthcare worker 3]
3	I know what my CD4 count is (and should be).	Barnes et al, 2013; Swendeman et al., 2009; Jena, 2014	Knowing and Understanding - HIV	'*Your CD4 count must be 1 000. That's a normal person's CD4 count.'* [Adolescent, Focus group 1]
4	I know what my viral load is (and should be).	Barnes et al, 2013; Swendeman et al., 2009; Jena, 2014	Knowing and Understanding - HIV	'*Then someone would explain to him. It is when it is suppressed, the viral load is suppressed.'* [Healthcare worker 2]
5	I would recognise signs and symptoms of a decline in my health.	Van Staa, 2012; Schulman-Green et al., 2012	Knowing and Understanding - HIV	*'[B]ut if I miss them for about two days or a week I easily catch up like fever, throat or have pains like a sharp pain or something.'* [Adolescent 4, Male, 16 years]
6	I understand why I am taking antiretroviral treatment (ARVs).	Barnes et al, 2013, Swendeman et al., 2009; Sattoe et al., 2015; Van Staa, 2012; Buran et al., 2006; Jena, 2014	Knowing and Understanding - Treatment	*'I think if you are not taking your pills the virus increases in your body.'* [Adolescent, Focus group 3]
7	I know my regimen (tablets).	Barnes et al, 2013, Swendeman et al., 2009; Sattoe et al., 2015; Van Staa, 2012; Buran et al., 2006	Knowing and Understanding - Treatment	'*Yes I know all my tablets, how they look and their names.'* [Adolescent, Focus group 3]

ITEMS		LITERATURE REFERENCES	SUB-THEME	PARTICIPANT QUOTATIONS
8	I know which foods and drugs I cannot take with my ARVs.	Schulman-Green et al., 2012	Knowing and Understanding - Treatment	'[Y]*ou shouldn't take other drugs while you are using ARV's.*' [Adolescent 6, Female, 18 years]; '*Sometimes the doctor said that it is not necessary for him to eat before taking his tablets. He can drink it before he eats as well*.' [Caregiver 1, Grandmother]
9	I understand the consequences of not taking my treatment every day.	Van Staa, 2012; Cox et al., 2014	Knowing and Understanding - Treatment	'*You need to know that if you don't eat your pills what will be the consequences of that*.' [Adolescent 4, Male, 16 years]; *'I think if you are not taking your pills the virus increases in your body.'* [Adolescent, Focus group 3]
10	I know when and why the doctor or nurse changes my treatment.	Schulman-Green et al., 2012; Cox et al., 2014; Jena, 2014	Knowing and Understanding – Treatment	'*I don't know mine [ARVs] because they change them continuously*.' [Adolescent, Focus group 3]
11	I know what lifestyle and behaviours are healthy for me.	Van Staa, 2012	Knowing and Understanding - Behaviours	*'You should not just do anything like drinking alcohol, having unprotected sex because you can get pregnant and not reach your goals*.' [Adolescent 6, Female, 18 years]
12	I know how to contact the doctor or nurse, if necessary.	Van Staa, 2012	Knowing and Understanding – Health care system	*'I go when it is my date and when we have a club.'* [Adolescent 6, Female, 18 years]
13	I can get information about HIV when I need to.	Schulman-Green et al., 2012; Jena, 2014	Knowing and Understanding – Health care system	'*I like to come to the clinic because the doctors are telling us how we can take care of ourselves, and how we can take our medicine to fight with HIV.'* [Adolescent, Focus group 4]
14	I can tell which doctor or nurse at the clinic or hospital treats me.	Van Staa, 2012	Knowing and Understanding – Health care system	'*He knows the doctors and if he does not know then he asks, what is the name of that doctor?'* [Caregiver 1, Grandmother]
15	I know what will happen if I transfer to adult care.	Van Staa, 2012	Knowing and Understanding – Health care system	'*Many of them will be transferred now and we must prepare the others for adults now.'* [Healthcare worker 2]
1b BELIEVING AND VALUING				
16	I can have a normal long and healthy life.	Sattoe et al., 2015; Jena, 2014; Li et al., 2010	Believing and valuing – HIV, normalcy	*'You need to know that it is not the end of life when you are HIV-positive and you can achieve your dreams.'* [Adolescent 4, Male, 16 years] *'I feel free like normal kids.' [Adolescent 2, Male, 14 years]*

ITEMS		LITERATURE REFERENCES	SUB-THEME	PARTICIPANT QUOTATIONS
17	I can take care of my health on my own.	Sattoe et al., 2015; Modi et al., 2012; Jena, 2014	Believing and valuing – HIV, normalcy	*'If you are HIV-positive it's not the end of your life, just take it as it came to you, you just need to take care of yourself.'* [Adolescent 4, Male, 16 years]
18	I can live with the knowledge that I have HIV for the rest of my life.	Webel, 2012; Sattoe et al., 2015; Van Staa, 2012	Believing and valuing – HIV, normalcy	'*So being HIV is not disturbing. It's about who you are, it's about who you understand about yourself.'* [Adolescent, Focus group 5]
19	I can accomplish as much as other people without HIV.	Van Staa, 2012; Schulman-Green et al., 2012; Jena, 2014	Believing and valuing - Future	'*A person should take their pills and value their selves the way they did before they got sick, nothing has changed.'* [Caregiver 6, Mother]
20	Being spiritual (e.g. believing in God or ancestors) helps me to stay positive about myself and the future.	Webel, 2012; Sattoe et al., 2015; Li et al., 2010	Believing and valuing - Spirituality	'*For me it does influence, because some things, you use them in spiritual ways, you don't use them like stylish ways. So I am influenced by spiritual things.*' [Adolescent, Focus group 5]
Domain 2: Self-regulation *(Goal setting, self-monitoring, reflective thinking, decision making, planning and action, self-evaluation, emotional control)* Ryan & Sawin, 2009; Van Staa, 2012 ; Schulman-Green et al., 2012				
2a SELF-REGULATION AND PROBLEM SOLVING (level of independence or collaboration with caregiver)				
21	I notice if my body is not well (e.g. I am sick or have side-effects from my treatment).	Cincinnati Children's Hospital, 2007; Swendeman et al., 2009; Modi et al., 2012	Self-regulation - Treatment	*'Monitoring yourself, you must make sure that if you have something wrong you go to the clinic, something that you are not sure of.'* [Adolescent 6, Female, 18 years]
22	I know when I am doing well on my treatment.	Schulman-Green et al., 2012	Self-regulation - Treatment	*'I need to manage them and have time for them, let's say for example, take them now and then not take them some other time, and not take them for about a week or two days, because that comes back and make me sick, but not that I become sick and lie down, but if I miss them for about two days or a week I easily catch up like fever, throat or have pains like a sharp pain or something, so I think it's caused by that.'* [Adolescent 4, male, 16 years]
23	Sometimes I decide not to take my treatment (e.g. when I feel tired of taking it or when I am going to a party I do not take my treatment) *(REVERSE)*	Sattoe et al., 2015; Cox et al., 2014; Jena, 2014	Self-regulation - Adherence	'I *was like no man, I do not want to take the tablets, I am healthy, why must I take tablets?'* [Adolescent, Focus group 1]
24	I take my treatment most of the time, even when I do not want to.	Modi et al., 2012; Schulman-Green et al., 2012	Self-regulation - Adherence	*'I feel sometimes, I feel like I'm feeling tired, but then I think the other side that I just have to drink my pills for my health.'* [Adolescent 3, Female, 13 years]

ITEMS		LITERATURE REFERENCES	SUB-THEME	PARTICIPANT QUOTATIONS
25	I only take my treatment when other people e.g. my parents tell me to take it *(REVERSE)*	Schilling et al., 2009	Self-regulation - Adherence	'*Now I look. I give now and swallow, open your mouth, lift your tongue.'* [Caregiver 3, Mother] '*My parents tell me to take the treatment.'* [Adolescent, Focus group 4]
26	I remember to take my tablets every day without someone reminding me (e.g. I use reminders like a pill box or my phone).	Cincinatti Children's Hospital, 2007; Sattoe et al., 2015; Modi et al., 2012	Self-regulation - Adherence	'*Nobody reminds me, I'm used to it, because seven o'clock I know it's my time to drink pills.'* [Adolescent, Focus group 5]
27	I plan how I will take my treatment when I am not at home (e.g. when I am visiting friends or if I go on a school camp).	Cincinnati Children's Hospital, 2007; Jena, 2014	Self-regulation - Adherence	'*Yes, I take my tablets with me, or I drink it at home, and then the morning when I come back, and then I drink it again.'* [Adolescent 3, Female, 13 years]
28	I decide who I want to tell about my HIV status.	Swendeman et al., 2009; Schulman-Green et al., 2012; Jena, 2014	Self-regulation - Disclosure	*'To disclose to your family, but to certain people not all of them, the ones you trust.'* [Adolescent 3, Female, 13 years]
29	I make plans on how to improve my health (e.g. exercise, eating healthy, not using alcohol or drugs, using condoms, studying).	Swendeman et al., 2009; Sattoe et al., 2015; Modi et al., 2012; Schulman-Green et al., 2012	Self-regulation - Behaviour	'*You should not smoke, not do bad things that other people wouldn't like and use your treatment every day, and not join friends who are bad influence because people will not like you.'* [Adolescent, Focus group 2] *'I should not focus on the outside things, focus on my studies so that I can succeed and be a nurse, the things that people are like the successful sports people.'* [Adolescent 5, Female, 14 years]
30	I attend clinic appointments on my own.	Sattoe et al., 2015; Modi et al., 2012	Self-regulation – Clinic attendance	'*The older ones tend to come on their own, the younger ones still come with their parents.'* [Healthcare worker 3]
31	I keep my clinic appointments.	Schulman-Green et al., 2012	Self-regulation – Clinic attendance	'*I have a calendar actually in my cupboard, and every time I write down the date.'* [Adolescent, Focus group 1]
2b COMMUNICATION				
32	I tell the doctor or nurse at the clinic if I experience any symptoms in my body.	Modi et al., 2012; Cincinnati Children's Hospital, 2007; Schilling et al., 2009; Schulman-Green et al., 2012	Communication – Healthcare worker	*'You get some who cannot stop talking and others whom you struggle to get information from.'* [Healthcare worker 1]
33	I ask the doctor or nurse if there is anything that I do not understand.	Sattoe et al., 2015; Modi et al., 2012; Cox et al., 2014	Communication – Healthcare worker	'*Yes, I like to come to the clinic because sometimes I ask questions that I don't know about my sickness.*' [Adolescent, Focus group 4]

ITEMS		LITERATURE REFERENCES	SUB-THEME	PARTICIPANT QUOTATIONS
34	I tell the doctor or nurse about my home situation, school, friends and romantic relationships.	Modi et al., 2012; Van Staa, 2012	Communication - Healthcare worker	'*I can talk to them because s/he knows about what I'm feeling.'* [Adolescent, Focus group 4]
35	I tell the doctor or nurse about private things (e.g. if I have missed my medication, if I am having sex or using drugs/alcohol or if I feel depressed/thinking too much about something).	Modi et al., 2012; Van Staa 2012	Communication - Healthcare worker	'*Everyone here at the hospital, I can tell them everything about myself.'* [Adolescent, Focus group 1]
36	I participate in decisions regarding my own health and treatment.	Schulman-Green et al., 2012	Communication – Healthcare worker, collaboration	'*Yes. I always tell them that this is not for me, it's for us. So everything that is here we have to share, and if you are having a problem, ask me, so that we can share this, because it's of no use you are coming in, you are bottled up, you are going out still bottled up.'* [Healthcare worker 3]
37	I talk to my parents or caregiver about HIV and other things.	Cox et al., 2014	Communication – Parents/caregivers	'*Yes, if there is something I don't like, or something happens, something like that, if I want to complain I just speak up*.' [Adolescent, Focus group 5]
38	I share my secrets with someone I trust (e.g. family member or close friend or a friend who also has HIV).	Webel, 2012; Li et al., 2010	Communication – Family/friends/peers	*'If you speak out what is bothering you to someone that you trust.'* [Adolescent, Focus group 3]
2c COPING WITH THE CONDITION				
39	I can cope with it if people say hurtful things about people living with HIV.	Swendeman et al., 2009; Sattoe et al., 2015; Schulman-Green et al., 2012; Jena, 2014	Coping - Stigma	'*You need not to think what people are saying about you, because you won't be healthy if you live your life for other people and not for yourself.'* [Adolescent 6, Female, 18 years] *'Sometimes like when the LO teacher teaches about the sickness, I just feel ashamed but sometimes it's hard for me to deal with things like that sometimes, but I manage, especially when they talk about the sickness.'* [Adolescent, Focus group 2]

ITEMS		LITERATURE REFERENCES	SUB-THEME	PARTICIPANT QUOTATIONS
40	I could manage to tell my parents or teacher if I am being bullied.	Van Staa, 2012; Jena, 2014	Coping - Bullying	'*Now I'm being still teased and bullied, so some children are picking up fight from me. Even though I tell the teachers, the teachers now they know that it's time for farewell, so they are saying all the things that I wasn't feeling good about the people who are teasing me, I must talk it out.'* [Adolescent, Focus group 2]
41	I set time aside to do things that I like (e.g. listening to music) to manage my stress.	Webel, 2012; Schulman-Green et al., 2012	Coping - Strategies	*'I also used to draw, in my silent moments. I also like yoga… just to destress.*' [Adolescent, Focus group 5]
42	I manage to take care of my chronic illness on my own.	Webel, 2012; Jena, 2014	Coping – Strategies/Accepting	'*[L]ike accepting yourself, be open and talk, you won't have a problem managing yourself if you are like that.'* [Adolescent 4, Male, 16 years]
43	I find strength from my past experiences or my beliefs when I am in a difficult situation.	Schulman-Green et al., 2012	Coping – Strategies/Accepting	'*I don't stop my dreams because oh, now I'm HIV-positive, so maybe I won't have kids one day, or you know, I can't be happy. I've got to go out, and I make sure I don't deny myself happiness because it is what it is, you know. Your reality is what you make it.'* [Adolescent, Focus group 1]
2d. GOALS Schilling et al. (2009); Schulman-Green et al., 2012 **The following are goals for me:** (SCALE: Never a goal; Sometimes a goal, Definitely a goal, I've met this goal)				
44	To be independent.	Schilling et al. (2009)	Self-regulation/Goals - Independence	'*I need to have my own time table, have time for everything, and have time for my pills and time for taking care of other things*.' [Adolescent 4, Male, 16 years]
45	To stay away from home overnight.	Schilling et al. (2009)	Self-regulation/Goals – Autonomy/managing treatment	*'… and with a sleepover at a friend's house, you're like I'm going to the bathroom.'* [Adolescent, Focus group 1]
46	To take care of myself so that I can live a normal life.	Schilling et al. (2009); Jena, 2014	Self-regulation/Goals – Managing illness/having a future	'*You don't like think about I have HIV and stuff, and then you don't, like when you play, you just don't feel that thing, that pain that you have HIV, maybe something that can be done.'* [Adolescent 2, Male, 14 years] '*You need to know that when you use your pills, you use them with the aim of reaching tomorrow alive, so that I can get what I want and achieve my goals.'* [Adolescent 6, Female, 18 years]

ITEMS		LITERATURE REFERENCES	SUB-THEME	PARTICIPANT QUOTATIONS
47	To understand why my viral load and CD4 is high or low.	Schilling et al. (2009); Jena, 2014	Self-regulation/Goals – Monitoring treatment	'*So they said your CD4 count is four, and they sent me here, and straight away on medication, and now mine is, I think 900 or something.'* [Adolescent, Focus group 1]
48	To feel good and have fun.	Schilling et al. (2009)	Self-regulation/Goals – Enjoying life	*'But now it's actually fun, ja, and I think it's a nice thing to get out and have fun.'* [Adolescent, Focus group 1]
49	To be in charge of taking my treatment.	Schilling et al. (2009)	Self-regulation/Goals – Autonomy/managing treatment	'*To drink your medicine, and not to forget.'* [Adolescent, Focus group 5]
Domain 3: Social facilitation, & resource utilisation *(Influence, support, collaboration)* Ryan & Sawin, 2009; Schulman-Green et al., 2012 (SCALE: Yes, certainly; Yes, probably; No, probably not; No, certainly not)				
50	I receive support from my family (e.g. my family remind me about taking my treatment, coming to the clinic, doing homework).	Swedenman et al., 2009; Schilling et al. 2009; Cox et al., 2014; Jena, 2014; Li et al., 2010	Social facilitation – Support – Family	'*Yes, my granny helps me, and my family.'* [Adolescent 3, Female, 13 years] '*My sister is very supportive. She always supports me in any situation I have. I trust her, and when I need anything, I can ask her. Sometimes I talk to my mother, but I can't tell my mother about everything.'* [Adolescent, Focus group 1]
51	I receive support from the healthcare providers (doctors, nurses, counsellors).	Swendeman et al., 2009; Cox et al., 2014; Jena, 2014; Li et al., 2010	Social facilitation – Support - Healthcare workers	'*Most of the people at the hospital inspire us, who lives with HIV, and encourage us, give us power to feed our hearts, but although it won't be cured, but we know there will be a way, someway, sometime, someday there will be a day out.'* [Adolescent, Focus group 1]
52	I receive support from my peers at the clinic (e.g. through the support group I can share my experiences/feelings).	Webel, 2012; Swendeman et al., 2009; Sattoe et al., 2015; Cox et al., 2014; Jena, 2014; Li et al., 2010	Social facilitation – Support – Peers/Groups	'*In this group, you can share your feelings, like how do you feel about the illness, and like outside you can't share it because you don't know who to talk to, and people will judge you.'* [Adolescent, Focus group 1]

ITEMS		LITERATURE REFERENCES	SUB-THEME	PARTICIPANT QUOTATIONS
53	I participate in sports or cultural activities at school or in the community in my free time.	Sattoe et al., 2015; Sattoe et al., 2015	Social facilitation / resource utilisation - Community	'*There is more like a youth group setup where the kids can go somewhere once a week that's near their house, where they can just kind of hang out and socialise and learn about things or do things together in a group. Just so that it's a bit more normal.'* [Healthcare worker 3]
54	I have good relationships with friends (e.g. at school or in the community).	Swendeman et al., 2009; Sattoe et al., 2015; Jena, 2014; Li et al., 2010	Social facilitation - Friends	'*Yes, I do have friends that I can trust. Because for me it's like ironic. Most of my friends have something, like a darker secret, and we are like that group.'* [Adolescent, Focus group 1]
55	I know where to find assistance or help in the community if I need it (e.g. a social worker if I have problems at home or school).	Schulman-Green et al., 2012	Social facilitation / resource utilisation – Community/Health care system	'*I've told my social worker and my social worker said that never mind of those people teasing you or bullying you, they'll just see in the future what the future will be holding them with.'* [Adolescent, Focus group 2]

5.4 CONCEPTUAL CLARIFICATION

I clarified definitions of key concepts in the study in order to facilitate further review of the items and group items in preliminary categories or domains. These definitions were based on the study theoretical framework, the literature and the data from the first phase of the study. The definitions were further adapted based on the feedback of experts in the third study phase. The initial definitions were:

- *Self-management:* The ongoing processes and behaviours adolescents engage in to take care of their chronic illness with the assistance of their caregivers and healthcare workers. It includes shared decision-making and responsibility among adolescents and their caregivers to achieve control of their condition, health and well-being through a range of activities and skills (Schilling et al., 2009:228; Ryan & Sawin, 2009:218). Self-management consists of the following domains: knowing and understanding; believing and valuing; self-regulation (subdivided into communication, coping and goals); and social facilitation and resource utilisation (Ryan & Sawin, 2009:220). Self-management is an evolving process with a trajectory beginning with adolescents being dependent on caregivers and gradually moving towards collaborative relationships and increased autonomy (Schilling et al., 2009:229).

  According to Aantjies et al. (2014:198), an empowerment model where patients take responsibility for their condition; and informed peers, caregivers and immediate family play an active support role is appropriate for chronic care delivery in low-income countries. This model may partially help to mitigate healthcare worker shortages.

- *Knowing and understanding:* Knowing and understanding disease characteristics, the treatment regimen, what constitutes healthy behaviour and how to navigate the healthcare system. Knowledge includes factual information and perceptions about a health condition and behaviour (Ryan & Sawin, 2009:220).

- *Believing and valuing*: Views or ideas about how one sees oneself living with the disease presently and in the future. This includes outcome expectancy (a belief that a behaviour will result in desired outcomes), self-efficacy (confidence in your ability to engage in behaviour under normal and stressful situations) and goal congruence (the ability to resolve confusion/anxiety occurring from contradictory/competing demands) (Ryan & Sawin, 2009:220).

- *Self-regulation*: It is the process of being in control, making independent decisions regarding one's health, managing various aspects of the disease (e.g. treatment, disclosure, and clinic appointments) independently and collaborating with others. Self-

regulation includes activities such as goal-setting, self-monitoring and reflective thinking, decision-making, planning for and engaging in specific behaviours, self-evaluation and management of physical, emotional and cognitive responses associated with managing a chronic illness (Ryan & Sawin, 2009:220).

- *Communication*: The ability to ask questions and engage with caregivers, healthcare workers and peers (Schulman-Green et al., 2012:141).

- *Coping*: Making sense of the disease and being able to handle stressful situations (Schulman-Green et al., 2012:141).

- *Goal setting*: Identifying areas for growth and improvement through self-reflection (Schilling et al., 2009:228).

- *Social facilitation and resource utilization*: Support received from family, healthcare workers and peers, participation in community activities and utilising community resources. It includes concepts of social influence, social support, and negotiated collaboration between individuals, families and healthcare providers. Social facilitation occurs within relationships and enhances an individual's capacity to change (Ryan & Sawin, 2009:20). Individuals may vary in their ability and willingness to let others take a role in managing their illness and the individual resources they choose to activate is a personal process that can vary over time (Schulman-Green et al., 2012:141).

5.5 SUMMARY

In this chapter, the findings from the first phase of the study were discussed in the light of the literature. The researcher demonstrated how the findings were related to the literature that aided in the development of items that were grouped in preliminary categories or domains. Self-management and some of the key concepts related to self-management were defined. The list of items identified in this study phase and the definitions of key concepts were used in the third phase of the study to design the adolescent HIV Self-Management (AdHIVSM) instrument. The design and pilot-testing of the AdHIVSM instrument will be discussed in the next chapter.

CHAPTER 6
INSTRUMENT DESIGN AND PILOT TESTING

6.1 INTRODUCTION

During the third phase of the study, an instrument that is contextually appropriate to measure adolescent HIV self-management was designed through several procedures focused on refining the items for the instrument and grouping items into sub-scales/categories. The processes followed for data collection and analysis are described in chapter 3 and included a workshop with adolescents and caregivers, a Delphi survey with experts and pilot testing the developed instrument and other measures with adolescents.

The workshop consisted of three focus groups: one with younger adolescents, one with older adolescents and one with caregivers. The primary purpose was to present the groups with the identified list of 55 items and obtain feedback on whether the items were contextually, culturally and developmentally appropriate, resonated with their experiences and fully tapped all the components of adolescent HIV self-management. Further, cognitive questioning techniques were used to explore their reasoning when answering items. Items were changed and added based on the feedback of the participants, resulting in a revised list of 65 items that were presented to selected experts by using a Delphi survey.

The Delphi survey aimed to determine the item content validity and clarity, clarify the conceptual definitions of the components of self-management and ensure that the items were correctly grouped into categories. Based on the information collected, items with low relevance to the construct were removed and unclear items revised. The final list included 44 items.

The final list of items was translated with the remainder of the questionnaire into Afrikaans and isiXhosa and piloted with adolescents in the target group. The pilot test was used to establish whether the target group clearly understood the questions, to identify any mistakes or translation errors and to perform preliminary statistical analysis of the items. The findings of the abovementioned processes are discussed in this chapter.

6.2 PARTICIPANT CHARACTERISTICS

Participant characteristics for the workshop groups, Delphi survey and pilot test are depicted in Table 6.1.

First, seven adolescents and four caregivers were involved in the workshops. All the adolescents and three of the caregivers participated in the first study phase. Secondly, 11

experts took part in the Delphi survey. Two of the experts had participated in the first study phase. Thirdly, 33 adolescents participated in the pilot study of which 12 participated in either phase 1 or phase 1 and phase 2.

Table 6.1 Participant characteristics for phase three

Workshop	
Adolescents (7 participants)	
Gender	
Male	3
Female	4
Age group	
13 - 15	2
16 - 18	5
Home Language	
Afrikaans	3
English	2
isiXhosa	2
Race	
Coloured	4
Black	3
Caregivers (4 participants)	
Gender	
Female	4
Home Language	
Afrikaans	2
isiXhosa	2
Race	
Coloured	1
Black	3
Age	
Mean	36
Delphi survey	
Academics and healthcare workers (11 participants)	
Gender	
Male	1
Female	10
Age	
Mean	45
Years of experience in primary area of expertise	
Mean	15

Pilot study	
Adolescents (33 participants)	
Gender	
Male	11
Female	22
Pilot study	
Adolescents (33 participants)	
Age group	
13 – 15	18
16 – 18	15
Home language	
Afrikaans	9
English	6
isiXhosa	18
In school?	
Yes	30
No	3

6.3 FINDINGS

In this section, the lessons learned and the feedback provided by participants is discussed. Illustrative examples from the data are provided and decisions regarding revision or addition/removal of items are presented.

6.3.1 Adolescent and caregiver workshop

A list of 55 items grouped into three main domains and seven categories were presented to the adolescents and caregivers as explained in chapter 3. Each of the seven categories covered one of the identified self-management components, namely, *Knowing and understanding; Believing and valuing; Self-regulation; Coping; Communication; Goals; and Social facilitation*. The workshop sessions were audio-recorded and key transcriptions were made. Group facilitators made notes regarding the feedback of participants and each participant was given a hard copy of the items to record their responses to questions and rate the relevance of each item within the category. The feedback provided by the participants on the items and my observations were grouped into four themes: The influence of age; caregiver perspectives; clarity and relevance of items; response variability and response options.

6.3.1.1 The influence of age

The age of the adolescents seemed to influence how they responded in several ways. Firstly, there was a difference in confidence between older and young adolescents when providing

feedback on the items. Secondly, adolescents' responses and their cognitive processes when interpreting the items differed according to age. Thirdly, when examining participant responses, older adolescents seemed to demonstrate more independent behaviours and less communication with caregivers.

The responses of older and young adolescents regarding whether items should be rephrased were markedly different. The young adolescents had no comments or suggestions for rephrasing items and reported that all the items were very clear to them. The older adolescents interrogated most of the statements and discussed the meaning of statements amongst each other. They were less likely to accept a statement as it was presented.

For the first question "I can describe the future consequences/concerns of my illness (HIV)", the response of one of the young adolescents was:

> *Yes, certainly, because it is important… my concerns of my health is important to me.*

The older adolescents responded with comments such as:

> *I understand do I know the consequences of my illness in the future… I do not know the consequences*.
>
> *The word 'concerns' is confusing.*
>
> *I was thinking what will happen in the future as I grow older, like it can turn into AIDS and then I can die.*
>
> *Nobody really knows what the future hold.*

Young adolescents therefore responded 'yes, certainly' where the older adolescents were more likely to respond 'yes, probably' or 'no, probably not' to some of the items. For the question, "I know which foods and drugs I cannot take with my ARVs", one of the young adolescents responded: '*Yes, certainly, unhealthy food.'* In the older adolescent group, this question led to a discussion. They were not certain about what foods they cannot consume with their ARVs. One adolescent said that a person cannot eat too much junk food and that one should not smoke drugs like tik (crystal methamphetamine) and dagga (cannabis). "Drugs" were interpreted as being substances such as tik and dagga by some, although one of the adolescents mentioned that it can include medications. They also said that one should not drink '*gas*' (carbonated soft drinks) and coffee with the tablets. An older adolescent suggested that an additional question be added regarding knowledge about the times of taking their ARV's since some of them were told that if they delay taking their treatment by one hour, they cannot take a dose for that day.

I observed that young adolescents tended to give less thought to individual words in statements and answered based on their overall interpretation of the item, where older adolescents tended to interrogate or reflect on words within statements. Lippman et al. (2014:35) also found that adolescents, particularly younger adolescents, were willing to provide responses even if they were not able to fully articulate their understanding of the question and provide a reason for their answer. Older adolescents were therefore more forthcoming to provide feedback on the items, which may be due to them being more confident or because their cognitive abilities were more developed. I made similar observations during the individual interviews and focus groups in the first phase of the study. It is, therefore, important that items should be as clear and unambiguous as possible. However, young adolescents may still have more positive responses compared to older adolescents due to them not interrogating the items deeply and this should be kept in mind when analysing participant responses.

When interrogating adolescents' responses, young adolescents had higher mean item ratings for knowledge, communication, coping and social support compared to older adolescents. Older adolescents had higher scores on beliefs, self-regulation and goals. It was noted from the item ratings that the older adolescents demonstrated more independent behaviour than the young adolescents and communicated more with peers than with caregivers. For the question, "I attend clinic appointments on my own", older adolescents answered, 'yes, certainly' and the young adolescents commented:

> *I go with my mother, because it is too far from where I stay so my mother says it is risky to go alone.*

> *I do not feel comfortable to go to clinic appointments alone, I always go with my mother.*

Regarding the question, "I talk to my parents or caregiver about HIV and other things", young adolescents responded:

> *Yes, I do tell my parents and then they will help you to get through with what you are struggling with.*

> *I do talk to my mother because she knows everything about HIV.*

Older adolescents responded that they do not really talk to their parents or caregivers since not all parents are well-informed and they either did not feel comfortable talking to them or did not get the opportunity. One older adolescent said:

> *I only speak in the group* [adolescent support group]*, only my mother knows* [about my HIV status] *and we do not have that relationship and there are always other people involved.*

It appeared as if the adolescent-caregiver relationship was closer for the young adolescents and they were still more reliant on their caregivers. A difference in responses and means scores on sub-scales between older and young adolescents may indicate that age may influence self-management, depending on the component of self-management. With regards to measurement, items elicited different responses which is desirable for item variability. However, these item ratings and question responses need to be interpreted with caution due to the small sample size.

6.3.1.2 Caregiver perspectives

Three of the four caregivers who were involved in the workshop participated in individual interviews in the first phase of the study. They were mothers of HIV-positive adolescents and were also living with HIV. The caregiver who did not participate in the first study phase was an aunt of one of the adolescents with whom he had stayed for a long time.

With regards to item content, feedback from caregivers indicated that they may not be well-positioned to answer questions related to self-management on behalf of their adolescents. They may underestimate or overestimate the adolescents' ability to self-manage. Further, it was noted that HIV-positive caregivers self-identified with many of the questions and tended to answer questions on behalf of themselves. Caregivers and adolescents' interpretation of certain items also differed, resulting in mixed feedback regarding the relevancy and clarity of some items.

A number of caregivers did not know how to answer on behalf of their adolescents. For the question, "I understand the consequences of not taking my treatment every day", one caregiver answered: '*No, probably not since my child does not take his pills very well.'* Caregivers may also underestimate the ability of the adolescent to deal with difficult situations. In the section on coping, caregivers' ratings of the adolescent's coping were lower than the adolescents' ratings. Concerning whether they can cope if someone say hurtful things about people living with HIV, one caregiver responded: '*No probably not. I will not interfere, I will just be quiet and not say anything'*, where the adolescent responded*:*

> *Yes I can because we are all the same, even do not listen to people to what they say, some people will say nasty things, you are the same and it is just the virus inside of you.*

In the abovementioned example, the caregiver interpreted coping as being an active coping response where the adolescent used an example of passive emotion-focused coping. The accuracy of caregivers' responses depends on how well they know their adolescents and whether the question relates to an observable behaviour (Lippman et al., 2014:37). However, even if a caregiver knows the adolescent very well, there may be differences in their reasoning when selecting an appropriate answer.

Caregivers tended to answer questions on behalf of themselves instead of on behalf of the adolescent. This occurred specifically towards the end of the list of items since they may have forgotten that the focus was on the adolescent. For example, when comparing the answers of the adolescents and caregivers for the questions concerning goals, more than one caregiver answered that the adolescent 'had achieved the goal', where the adolescent answered 'definitely a goal'. For the item, "It is a goal for me to take care of myself so that I can live a normal life", one caregiver commented:

> *Never a goal, I take my pills, the only thing I have a problem for now is that I do not use a condom.*

In the caregiver group, this question elicited a discussion around the use of condoms, since some of the mothers struggled to consistently use condoms with their partners. For the question about whether the adolescent would tell the doctor or nurse about private things, one caregiver commented: '*We do not say everything, we always say yes, even if we do not do it.'* Lippman et al. (2014:37) observed that caregivers sometimes were unable to separate their own opinions and experiences from those of their adolescents. This is particularly the case in this context where most of the caregivers were also living with HIV. It does, however, lend support for the item validity and indicates that some components of adolescent HIV self-management may also apply to adults living with HIV.

For some items, the interpretation of caregivers and adolescent differed, resulting in different feedback regarding the relevancy and clarity of the items. For example, one of the items related to goals concerned whether it was a goal for the adolescent to stay away from home overnight. This was intended to measure their independence to be away from home and still manage their treatment. Both young and older adolescents commented that the item could be deleted. Some older adolescents laughed at this question and thought it related to going out clubbing and they felt it depended on one's age. One young male adolescent felt that it was not safe for him to stay out at night and the young female adolescent said she had met this goal. On the other hand, caregivers related this to being responsible since the adolescent would have to take their treatment on their own:

> *I understand it as to be responsible, if I go to sleep over night I still need to take responsibility take my treatment, take care of yourself.*

Caregivers felt that the item, "It is a goal for me to feel good and have fun" should be changed to '…feel good and have fun in the right way.' Caregivers were therefore conscious that 'having fun' may include behaviours that are not acceptable. Conversely, adolescents commented that they need to feel good and have fun.

> *Yes, because of this people may feel permanently depressed*. [Older adolescent]

Yes, definitely. Because I also want to feel good and have fun like other people. [Young adolescent]

Feedback from the perspective of caregivers therefore support the notion that adolescents should answer questions themselves (Van Staa, 2012:282). Caregivers may not be able to answer questions on their behalf and may interpret questions differently.

6.3.1.3 Clarity and relevance of items

Feedback regarding the clarity and relevancy of items assisted in refining the items for the target group. Questions that were clear and specific were better understood by participants. The quality of the data may be compromised if a question lacks specificity. For example, the question "I can have a normal long and healthy life", were left unanswered by some adolescents since they did not know how to answer it. One adolescent said: *'I do not know what the future holds for me, what will happen that can affect my health'*; another responded: '*Why normal?*' The word 'normal' was specifically included due to the emphasis placed on being normal in the qualitative data. However, it appeared that using the word 'normal' in the item made the adolescents feel that they were being compared to other people and slightly offended some of them. It was suggested that 'normal' be removed from the sentence. One of the caregivers responded: *'Yes, because if you take your tablets, eat healthy, do the right thing then you can live.'* The question was therefore ambiguous and had to be revised to ensure that it is more specific with regards to the meaning.

Some questions were confusing and required clarification. For the question, "I would recognise signs and symptoms of a decline in my health", both older and young adolescents were not sure what signs and symptoms would indicate a health decline. The older adolescents mentioned that it could be physical symptoms but that they did not know any. One adolescent mentioned symptoms of a cold sore in the mouth, fever and coughing. Another said that she had not been sick in three years. One adolescent said that her mother would recognise when there is something wrong with her, for example, when she does not want to eat. The young adolescents did not understand this question at first, but one adolescent answered, *'When you have headaches and stomach aches'* after the isiXhosa translator explained it as 'signs of being unhealthy.' This also indicates that questions need to be on a literacy level that is understandable for both young and older adolescents. There may be differences in how older and young adolescents interpret questions based on different literacy levels if the reading-level of the questions are set too high. Another question that needed clarification was "I know my regimen (tablets)". The caregivers were not certain what 'regimen' means. They interpreted it as first-line or second-line treatment. There was also uncertainty if the question meant the names of the tablets.

Adolescents seemed to interpret items better when the items were connected to their experiences/behaviour and if examples were provided. For example, older adolescents responded that the questions related to communication were more straightforward. These included questions such as “I ask the doctor or nurse questions if there is anything that I do not understand.” However, if too many examples were used, some participants answered based on part of the question only. For the question, “I tell the doctor or nurse about private things (e.g. if I have missed my medication, if I am having sex or using drugs/alcohol or if I feel depressed/thinking too much about something)”, one adolescent responded:

> *Yes, probably I will since my drugs does not affect me physically so it must affect me in some other way and psychological and emotional problems lead to suicide.*

She added that she will definitely not tell the doctor if she has missed her medication, since she will be reprimanded.

Some double-barrelled questions were identified, for example, “I know when and why the doctor or nurse changes my treatment.” The adolescents felt that this question should be separated into two questions.

Items must also have clear reference points, otherwise participants create their own. For the question of whether being independent is a goal for them, many adolescents responded that it definitely was a goal. Some of the older adolescents felt that this question was too vague because:

> *There are two types of independence. When you are an adult and the independence that we have when we do not ask others for help, for example, asking a friend to blow your hair. Then there is the other independence also like do you pay rent?*

The young adolescents answered as follow:

> *It is definitely a goal, because everyone want to be alone, and at home also so you also need to have time by yourself.*

> *It is nice to be alone so that you can experience things alone and not with your mom.*

There were therefore clear differences in reference points regarding this question. Older adolescents viewed this question as not needing help from others, whereas the young adolescents viewed it as having time alone. Another question that needed reference points or examples was “I participate in decisions regarding my own health and treatment.” Adolescents did not understand words such as ‘participate’ and ‘decisions’. An older adolescent suggested adding an example to the question:

Perhaps an example should be included, for example, being asked whether they should switch you to once daily dose. I do participate because I said I wanted to go to the once a day dose.

With regard to relevancy, some less relevant items were also identified. For the question "I can tell which doctor or nurse at the clinic/hospital treats me", adolescents and caregivers provided similar responses. Adolescents who participated in the first study phase mostly received care by dedicated healthcare providers and appeared to have close relationships with them. However, from the adolescents' and caregivers' responses to this question, it appeared that whom they were seen by depended on the clinic context. There was not necessarily continuity in healthcare providers from visit-to-visit and they did not have a choice regarding which healthcare provider they wished to see. It may therefore not be relevant for adolescents to know which provider treats them in this context. Participants expressed it as follows:

Do we have a choice? Basically they just take our files and call our names. [Older adolescent]

Some doctors treat the children badly, the doctor will tell everyone about the stuff and the children get scared and do not want to eat their tablets. [Young adolescent]

There is nobody specific, you meet different people. [Caregiver]

This is not important, any person can take your folder. [Caregiver]

Another item that appeared to be less relevant was the question related to what will happen when the adolescent transfers to adult care. Not everyone agreed that this was important. Adolescents felt that they should be informed about this by healthcare providers at the clinic. One adolescent mentioned that this means that they will simply receive their treatment and go home and another said: *'The doctors are more hard core, they do not care, you are just on your own.'*

Participants' feedback related to item relevancy and clarity were used to identify items with less relevancy in the context and refining the clarity of items, for example, ensuring that the items were not double-barrelled, adding examples were appropriate and making sure that the wording was on an appropriate reading level.

6.3.1.4 Response variability and response options

Concerning variability in responses, it was noticed that none of the participants selected the option, 'No, certainly not' for any of the statements. Since most the items were positively phrased, this may be explained by the small sample size and that the selected group consisted

of participants who regularly attended support groups at the clinics. Regular attendance of the clinic may mean that the participants have better self-management and therefore had positive responses. Since all the adolescents were infected perinatally, most of them have been attending the clinic from a very young age and have received numerous messages from caregivers and health care workers about what constitutes desirable behaviour. They may therefore have been inclined to select socially desirable response options. On the other hand, it may also indicate the participants selected positive options without reflecting more deeply on the questions.

Social desirability can be addressed through including high threshold items which are more difficult for participants to respond to affirmatively (Lippman et al., 2014:40). The list of items contained some negatively phrased items, for example, “I only take my treatment when other people e.g. my parents tell me to take it”. Some adolescents identified that this question was similar to the previous question “I remember to take my tablets every day without someone reminding me (e.g. I use reminders like a pill box or my phone)”. All except one participant provided opposite answers for these two questions e.g. ‘yes, certainly’ vs ‘no, certainly not’. One participant answered ‘yes, probably’ for both questions. DeVellis (2012:105) noted that negatively phrased items are sometimes difficult for participants to answer due to changing the answer polarities. Although reverse/negative items may therefore help to limit social desirable responses, they may also confuse participants. Further, frequency scales capture greater variability, especially for socially desirable items (Lippman et al., 2014:40). It was therefore decided that it would be better to change the scale to frequency responses if the item concerned behaviours.

The data from the workshop therefore helped the researcher to i) refine items so that they were clearer and concrete, with specific reference points, avoiding words that could lead to misunderstanding; ii) revise items that were ambiguous or open to multiple interpretation and iii) add additional items as suggested by the participants.

Following the workshop, 10 items were added to the questionnaire. These items included questions such as “I know at what times I should take my treatment”; “I know if I can take my tablets with or without food”; and “To make the right decisions is a goal for me.” There was also a discussion amongst the adolescents about using alcohol and drugs to cope that led to the inclusion of the question: “I manage my stress by eating too much junk food, using drugs (e.g. dagga), smoking cigarettes or drinking alcohol.”

Although participants deemed some items to be less relevant, these items were retained for the expert review. This allowed for an exhaustive list of items related to adolescent HIV self-management. It was decided in collaboration with the study supervisors that items will only

be removed if the same items also obtained low relevancy ratings by the experts. The number of items included for expert review was therefore 65 items.

6.3.2 Delphi survey

A document containing the list of 65 items that were revised following the workshop and the definitions of concepts/item category names were circulated to a group of experts for review. The group included two healthcare workers who participated in the first study phase and 10 other experts. Their expertise included adolescent psychiatry, paediatrics, school nursing, HIV management, nursing, self-management and psychometrics. Of the 12 experts who were approached to participate, 11 experts responded with feedback and one of the experts eventually declined due to time constraints.

As explained in chapter 3, the experts rated the clarity and relevancy of each of the items on a scale of 1 through 4: irrelevant to very relevant; very unclear to very clear. The items were presented according to the categories. Experts could also provide qualitative comments on each of the items and the concept definitions. The feedback from the experts was captured in Microsoft Excel. The clarity and relevancy rating of each item was calculated and the comments summarised. These ratings were used to calculate item and scale relevancy in order to ensure that the items adequately represent the construct of self-management and the components thereof. Further, the list of 65 items could be shortened so that only highly relevant items were included. Through this process items that were unclear were also identified and revised.

6.3.2.1 Item relevancy

Item relevancy relates to the content validity of the items and how well the items tap the concept of self-management. A content validity index was calculated for each item. The content validity index for individual items (I-CVI) is the proportion of experts who gave a rating of 3=relevant or 4=very relevant to an item. As explained in chapter 3, it was decided that the minimum acceptable index would be 0.8. This meant that no more than two experts gave a rating of 1=very irrelevant or 2=irrelevant.

Of the 65 items, only two items had a rating of less than 0.7. These items were: “I know what will happen if I transfer to adult care”; and “To make the right decisions is a goal for me”. These two items were eventually removed since the experts indicated that the transfer to adult care will depend on the setting and that not all adolescents formally transition from paediatric care to adult care. The question related to transfer was also identified by the adolescents as less relevant. In addition, both questions were considered broad and vague. There were nine items with a rating of 0.8. Although acceptable according to the literature, these items were reviewed in collaboration with the study supervisors based on the comments from the experts.

Where there was overlap with other items or where item clarity could not be improved, the items were removed. Two items with a rating of 0.8 were retained and the wording adjusted based on the expert feedback. These items were: “I know the names of my ARVs”; and “My faith helps me to stay positive about myself and my future”. Some items with a relevancy rating of 0.9 or 1.0 were also removed if they were found to overlap with other items and if the item clarity index was very low. Expert comments were considered even if the items had very high relevancy ratings. One example was the question: “I know what my CD4 count is and should be”. With this item, some of the experts indicated that this may not be communicated to adolescents since routine CD4 monitoring is not done in practice anymore. This question was therefore removed. A total of 21 items were removed from the scale. Care was taken to ensure that the retained items still covered all the domains/categories of self-management.

Based on the expert feedback, it was decided to include a self-management behaviour category since certain items were more clearly measured as a behaviour. The final questionnaire included 44 items categorised according the self-management domain and sub-domain as depicted in Table 6.2. The content validity of the whole scale, also called the average content validity of individual items (S-CVI/Ave) was 0.94. The minimum acceptable standard is 0.9. This indicated that the items in the original 65 item scale were relevant and valid as rated by the experts and meant that a second round of review was not necessary. Further, the S-CVI/Ave of the individual sub-scales/domains following the removal of irrelevant items were above 0.9. The researcher circulated the results and the revised items to all the experts for any further feedback. Two experts responded with minor comments which were incorporated.

6.3.2.2 Item clarity

Experts could rate the clarity of each item: 1=very unclear through 4=very clear. An item clarity index was calculated. Eight items had a clarity rating of less than 0.8 and another eight items had a clarity rating of 0.8. Items with a low clarity rating and a low relevancy rating (below 0.8) were removed. Where the item had a low clarity rating, but a high relevancy rating e.g. 0.9 and above, the clarity was improved based on the expert feedback and a discussion with the study supervisors. Most of the feedback regarding item clarity related to improving the language to be on the level of the adolescent and to remove double-barrelled questions that could be confusing. For example, the question: “I know what my viral load is and should be” was separated into two items to improve the clarity.

Feedback was also provided on the scale used. The response options, ‘yes, definitely’ through ‘no definitely not’, had to be simplified. Based on this feedback, the scale was modified to range from ‘strongly agree’ through ‘strongly disagree’ or frequency response options such as

'never' through 'always' as suggested by the experts. The questions related to goals were also rephrased to fit with the abovementioned scales.

General comments included that many of the items had complex language construction and were too long. One expert specifically commented that the adolescents who live with HIV come from poor socio-economic backgrounds with interrupted schooling and many executive function (cognitive processes necessary for behaviour control) challenges that affect their language and literacy. The questions therefore needed to be simplified and more layperson-friendly. Some questions addressed similar issues and could be refined further. Other suggestions included asking open-ended questions to assess whether the adolescents truly are knowledgeable about the aspects of their disease. One expert commented that the examples complicated the questions and that the measure should perhaps be pilot tested with and without the examples and the results compared to see if the examples makes a difference. However, based on the adolescents' feedback that examples aided their interpretation and a discussion with translators from the Language Centre, it was decided that the examples were meaningful. All decisions and changes to items were clearly documented.

Table 6.2 Retained items under each domain and sub-domain

Domain	Sub-domain	Nr	Item	I-CVI
Knowing and understanding	Health and illness	1	I know the signs and symptoms of my illness (HIV) (for example, when I am sick or have side-effects from my ARVs).	0.9
	Health and illness	2	I can get information about HIV.	1.0
	Health system	3	I know the date of my next hospital or clinic appointment.	1.0
	Health system	4	I know how to contact the doctor or nurse if I need to.	0.9
	Treatment/illness	5	I know what my viral load is.	1.0
	Treatment/illness	6	I know what my viral load should be.	1.0
	Treatment	7	I understand why I am taking ARVs.	0.9
	Treatment	8	I know the names of my ARVs.	0.8
	Treatment	9	I know at what times I should take my ARVs.	1.0
	Treatment	10	I know what to do when I miss the time to take my ARVs.	1.0
	Treatment	11	I understand what will happen if I don't take my ARVs every day.	0.9
Believing and valuing	Beliefs about self, illness & future	12	I can achieve as much as other people who don't have HIV.	0.9
	Beliefs about self, illness & future	13	My faith helps me to stay positive about myself and my future.	0.8
	Beliefs about self, illness & future/self-efficacy	14	I am confident I can take care of my health.	1.0
Self-regulation	Decision-making/problem-solving	15	I decide by myself whom I want to tell about my HIV status.	1.0
	Treatment/self-monitoring	16	I rely on other people to remind me to take my ARVs.	1.0
	Treatment/goal congruence/self-monitoring	17	Other things interfere with my plans to take my ARVs (for example, when I go to a party or sleepover or when I do drugs).	1.0
	Treatment/planning	18	I plan how to take my ARVs when I am not at home (for example, when I am out with friends or on a school camp).	1.0
	Coping/stigma/emotions	19	I can cope with it if people say nasty or hurtful things about people living with HIV.	1.0
	Coping/disclosure/stigma/ emotions	20	I would cope if I tell someone about my HIV status and that person didn't accept it or ignored me.	1.0
	Coping/bullying	21	I would tell my parents or teacher if I were being bullied (physically or verbally) and it felt out of my control.	0.9
	Coping/stress	22	Doing things I like (for example, listening to music, reading or playing sport) helps me to cope.	1.0

Domain	Sub-domain	Nr	Item	I-CVI
Self-regulation	Coping/stress/emotions	23	Things like eating junk food, smoking cigarettes, drinking alcohol or taking drugs help me to cope.	0.9
	Goals/life/social	24	I aim to independent (taking care of myself).	1.0
	Goals/illness/treatment	25	I aim to understand why my viral load is high or low.	1.0
	Goals/life/social	26	I aim to enjoy life, feel good and have fun.	1.0
	Goals/life/social	27	I aim to be successful (for example, finishing school, studying further or getting a job).	1.0
	Goals/self-efficacy	28	I feel confident that I can meet my health and life goals.	1.0
SM Behaviours	Health and illness	29	I do things to improve my health (for example, by exercising or eating healthy foods).	0.9
	Health system	30	I attend clinic appointments on my own.	1.0
	Health system	31	I attend clinic appointments on scheduled dates (for example, I use a calendar, phone or my clinic card to remind myself).	0.9
	Treatment adherence	32	I take my ARVs even when I don't want to (for example, when I feel depressed or am tired of taking them).	1.0
	Sexual behaviour	33	My partner and I use a condom when we have sex.	0.9
	Collaboration/participation	34	I take part in decisions about my health and treatment (for example, I tell the doctor or nurse what I think and we make decisions together).	1.0
	Communication/participation	35	I ask the doctor or nurse questions when there is anything that I don't understand.	1.0
	Communication/participation	36	I tell the doctor or nurse how I am feeling (for example, when I feel sick, depressed or have side-effects because of my treatment).	1.0
	Communication/participation	37	I tell the doctor or nurse when I miss a dose of my ARVs.	1.0
	Communication/participation	38	I tell the doctor or nurse about private things (for example, If I am having sex or using drugs or alcohol).	1.0
Social facilitation	Relationships/support	39	My family support me to live with HIV.	0.9
	Relationships/support	40	Doctors, nurses and counsellors at the clinic support me to live with HIV.	0.9
	Relationships/support	41	Other adolescents at the clinic (for example, in my support group or club) support me to live with HIV.	1.0
	Relationships/support	42	I have regular contact with friends (for example, at school or in my community).	1.0
	Community participation	43	I participate in activities at school or in my community.	1.0
	Community assistance/resource utilisation	44	I would find help in my community if I needed it (for example, a social worker if I had problems at home or at school).	1.0

6.3.2.3. Conceptual definitions

Experts were provided with an opportunity to comment on the conceptual definitions of the item categories/domains. Changes suggested were limited and are briefly summarised.

With regard to the broad definition of A*dolescent HIV self-management*, one expert felt that self-management is an internal process rather than something adolescents do with the assistance of caregivers. However, another two experts mentioned that the people assisting adolescents with self-management should be expanded to include, caregivers, healthcare workers, family, friends, peers and educators. Based on the theoretical framework of the study, it was agreed that adolescents self-manage in collaboration with other people and therefore the definition was expanded to include the people suggested.

Knowing and understanding: In this category it was suggested that adolescents' knowledge of the consequences of poor health behaviours be added. Further, adolescents should not know the healthcare system, but know how to access/navigate the healthcare system. Another suggestion was that the definition should not include the same words as those being defined (i.e. knowing and understanding), but that other words such as 'awareness' or 'comprehension' should be used.

Believing and valuing: It was suggested that the word 'valuing' should be explained, for example, what is considered important. Beliefs should not only focus on living with HIV, but also on the adolescents' expectation for the future. There were also suggestions regarding making the definition more specific, for example, beliefs about treatment effectiveness.

Self-regulation: Suggestions included adding 'recognizing illness and the need for further consultation' to the definition and specifying 'treatment as prescribed', since 'managing treatment independently' may be interpreted to mean that the individual is free to change their treatment. The expert in self-management disagreed with the definition of this component and stated that the management of various aspects of disease are self-management behaviours. Self-regulation is monitoring one's condition, problem-solving and setting goals. It was therefore decided to include another separate sub-domain for self-management behaviours. In addition, the sub-domain 'communication' was moved to 'social facilitation' as it was perceived to fit meaningful in terms of the essence of social facilitation - see definition in Table 6.3. However, most of the communication items were categorised under self-management behaviours as suggested by one of the experts, since it was observable behaviours.

Social facilitation: Some experts felt that social facilitation extended beyond the persons listed, for example, neighbours, educators and anyone with whom the adolescent interact.

The conceptual definitions were refined based on the feedback from the experts and the final definitions are listed in Table 6.3.

Table 6.3 Revised conceptual definitions

Concept	Revised definition
Self-management	The processes and behaviours adolescents engage in to take care of their chronic illness with the assistance of their caregivers, health workers, family, friends, peers and educators. Self-management consists of the following domains: knowing and understanding; believing and valuing; self-regulation; and social facilitation.
Knowing and understanding	An awareness and comprehension of your disease, treatment regimen, accessing the healthcare system and what constitutes healthy behaviour.
Believing and valuing	Views or ideas about how you see yourself and living with your disease presently and in the future; including what you consider important or beneficial and the expected outcomes of treatment or health behaviours.
Self-regulation	Being in control, recognising illness and the need for further consultation, making independent decisions regarding your health and collaborating with others. Self-regulation includes decision making, planning, goal-setting, self-evaluation and coping.
Social facilitation	A process that occurs within relationships you have with caregivers, family, health workers, friends, peers and educators. It includes social influence and social support, for example, discussions in which persons with knowledge advise and encourage you to carry out specific health behaviours and provide informational, emotional or other support to manage HIV in general. It includes communication (the ability to ask questions and engage) with caregivers, family, peers, friends, healthcare workers and educators.
Self-management behaviours	Behaviours involved in managing various aspects of your disease (e.g. taking treatment as prescribed, disclosure, healthy behaviours, using a condom when having sex, participating in decisions about their health and attending clinic appointments).

6.3.3 Pilot test

The adolescent HIV Self-Management (AdHIVSM) scale and the other scales and questions included in the final questionnaire was pilot tested with 33 adolescents of the target population. The primary purpose of the pilot test was to identify questionnaire translation mistakes, to ascertain whether the target group clearly understood all the questions, to determine how long participants took to complete sections of the questionnaire and the entire questionnaire and to clarify the procedure for data collection. The secondary purpose of the pilot test was to

perform preliminary statistical analysis to investigate the results of individual items of the AdolHIVSM scale.

6.3.3.1 Procedural considerations

Thirty-four adolescents were conveniently sampled at the two study sites, one refused and 33 completed the questionnaire. One adolescent completed half of the questions since he had to see the doctor and did not return due to another appointment. Telephonic consent was obtained from caregivers for those adolescents younger than 18. None of the caregivers refused participation. Of the 33 participants, 12 had participated in either phase 1 or phase 1 and phase 2.

Questionnaires took approximately 45 to 90 minutes to complete. Most adolescents chose to complete the English questionnaire despite their home language being Afrikaans or isiXhosa. The isiXhosa-speaking participants felt that the isiXhosa questionnaire was very long compared to the English questionnaire since explanations are longer in isiXhosa. Where fieldworkers assisted adolescents by reading questions and explaining some of the questions, it took longer to complete. After the participants completed the questionnaire, the fieldworkers checked if all the questions were answered. Participants left some questions unanswered, which may be due to the length of the questionnaire or the lack of space between questions. None of the adolescents complained about the length of the questionnaire, although for some, it could be observed in their body language that they became tired. Participants were briefly interviewed after the completion of the questionnaire to explore their understanding of certain questions, especially where discrepancies in responses were identified.

At one study site, the adolescents completed the questionnaire while they were waiting to be seen by the healthcare provider. The adolescents at the other study site came in the afternoon and there was limited time since they had to attend a group session and see the healthcare provider. The researcher arranged for those who wanted to participate to complete the questionnaire during the group session.

It was clear that the questions related to sexual behaviour, alcohol and drugs were sensitive and some adolescents chose the option ‘I choose not to answer’ for many of the questions, since it was one of the response options. Following a discussion with one of the adolescent participants on how to approach private information, it was decided that the fieldworkers should give the adolescents more privacy to complete that section. It was also decided to exclude the response option ‘I choose not to answer’ from the final questionnaire since those adolescents who did not feel comfortable sharing the information might leave the question unanswered.

The participant consent/assent form requested permission from the participants to obtain information about their blood results, their medication and clinic visits from their patient folder. The viral load (VL), medication list and whether they missed a clinic appointment was obtained from the participant's patient folder. Since VL is performed annually, many of the viral loads were not recent measures and were considered a possible limitation.

6.3.3.2 Amendments to the questionnaire

Typographical mistakes such as incorrect numbering and incomplete sentences were identified during the pilot study. For some questions, question text and directions were changed or emphasized; or response options amended. For example, the question "level of education" was changed to "highest grade completed" so that it was clearer and for the question "whom have you told you are HIV positive", two additional response options, 'nobody' and 'sexual partner' were added.

Many adolescents omitted questions due to the number of questions on one page. Adaptations to the questionnaire format were made in order create more space.

Some adolescents did not read the instructions before each question and completed all the questions irrespective of instructions stating that certain questions can be omitted if the answer to the first question was 'no'. Instructions were therefore emphasized (for example, made larger, placed in bold or underlined) to ensure that it stood out.

Very few of the adolescents could answer the question about the names of their ARV's. This question was removed since the researcher captured the information from the participant's patient folder.

A section in the questionnaire that took longer to complete was parental/caregiver involvement, since adolescents found it challenging to answer how frequently they interacted with their parent/caregiver. This section was removed to shorten the questionnaire. Parental involvement/support was partly measured in the *Health-Related Quality of Life* and *Resilience* measures.

Younger adolescents tended to choose extreme responses to the *Treatment self-efficacy* questions, for example, either '1=not at all confident' or '10=extremely confident'. It was decided to adapt the response options heading to include '5=somewhat confident'.

With the adherence to treatment questions, some discrepancies were noted, for example, saying that they never miss treatment and then selecting reasons for missing treatment once or twice a week. Adherence is considered a sensitive topic and difficult to measure using self-reports. These kinds of discrepancies may therefore be an expected finding.

On the *Strengths and Difficulties* (SDQ) section, many adolescents were uncertain about what 'fidgeting and squirming' means. Consequently, an additional word 'wriggling' was added to the English text. The isiXhosa and Afrikaans translations were kept the same as participants clearly understood the items.

The interpretation of one question on the AdHIVSM measure seemed to be problematic: "I decide by myself whom I want to tell about my HIV status." Some adolescents who had not yet disclosed were likely to select 'never'. For this item, the emphasis was on the decision-making process of disclosing and not whether they had disclosed. The Afrikaans and isiXhosa translations, however, did not seem to have interpretation ambiguity. Following a discussion with the Language Centre, it was decided to keep the item as is, since adding more words could further obscure the meaning. Therefore, no changes were made to the developed AdHIVSM measure following the pilot test.

No problems with the language translations were identified during the pilot study although only three participants completed isiXhosa questionnaires and only nine participants completed Afrikaans questionnaires. The isiXhosa and Afrikaans translations underwent a rigorous process of forward and backward translation by experienced translators and were again checked for accuracy by the fieldworkers. The isiXhosa-speaking fieldworkers felt that some of the isiXhosa sentences could be simplified since it was very 'academic'. Two of the fieldworkers made suggestions for changes that were sent to the Language Centre and the isiXhosa questionnaire was consequently slightly adapted.

6.3.3.3 Preliminary scale and item analysis

Reliability analysis was performed on the AdHIVSM scale and the other scales. The Cronbach's alpha of most the scales included in the questionnaire was acceptable (above 0.7) and is reported in Table 6.4. The scales that had a low internal consistency were the *Strengths and Difficulties* scale and the *Parental Involvement* scale. The *Parental Involvement* scale was removed from the final questionnaire as previously mentioned. The rationale behind this was that questions related to parental/caregiver involvement were also included in the *Health-Related Quality of Life (HRQOL)* and *Resilience* measures. There was a significant correlation between the *Parental Involvement* score and the sum-score of the items related to parental involvement on the *HRQOL* ($r=0.374$, $p=0.05$) that further supported the redundancy of the *Parental Involvement* scale.

With the *Strengths and Difficulties* scale, the sub-scale about hyperactivity had very low reliability. Item coding was checked and contrasting statements cross-tabulated to explore any inconsistencies. For example, the question "I am easily distracted. I find it difficult to concentrate" should have an opposite response from the question "I finish the work I am doing.

My attention is good". When cross-tabulated, only 9.4% had a true opposite response 'certainly true' versus 'not true' and 15.6% responded 'certainly true' on both questions which is a contradictory response. However, since this was an established measure and the pilot study included a small sample, no changes to these items were made.

Table 6.4 Reliability results of questionnaire scales

Scale	n	Cronbach's alpha in pilot study	Cronbach's alpha reported by authors/literature
Treatment Self-efficacy: 8 items	**32**	0.831	>0.9
Adolescent HIV self-management: 43 items	**28**	0.86	Above 0.7 is acceptable
Knowing and understanding (11 items: 1-4; 32-38)	30	0.812	
Believing and valuing (3 items: 5-7)	33	0.675	
Self-regulation (14 items: 8-17; 39-42)	31	0.560	
SM behaviours (9 items: 18-25; 43)	31	0.707	
Social facilitation (6 items: 26-31)	31	0.615	
Parental Involvement: 14 items	**28**	0.687	Above 0.7 is acceptable
Health Related Quality of Life (n=28): 27 items	**28**	0.843	Sub-scales 0.8 – 0.84
Physical activities and health (5 items)	31	0.721	
General mood and feelings (7 items)	31	0.731	
Family and free time (7 items)	31	0.773	
Friends (4 items)	31	0.561	
School and learning (4 items)	32	0.779	
Strengths and Difficulties: 25 items	**28**	0.546	Sub-scales 0.26 – 0.84
Emotional problems (5 items)	30	0.348	
Conduct problems (5 items)	32	0.521	
Hyperactivity scale (5 items)	31	-0.043	
Peer problems scale (5 items)	30	0.517	
Prosocial scale (5 items)	31	0.837	
HIV Stigma: 8 items	**28**	0.733	0.81
Resilience (CRYM-12): 12 items	**31**	0.845	0.84

Although no items were removed from the AdHIVSM scale at this stage, the researcher considered item variability. Items with little variability (e.g. where all participants agreed or disagreed), does not discriminate between low and high levels of the construct and therefore does not contribute to the reliability and validity of the scale. The means and standard

deviations of each item were identified and those with extreme means and zero, or close to zero variances were considered for exclusion. The lowest mean score was 2.19 ("I know what my viral load is") and the highest 3.86 ("I am confident that I can take care of my health") out of a maximum score of 4. Standard deviations were between 0.415 ("I am confident that I can take care of my health") and 1.343 ("I take my ARVs even when I don't want to (for example, when I feel depressed or am tired of taking them"). None of the items therefore had extreme means or variances close to zero.

The researcher explored the correlations between each respective item and the total sum score (without the respective item), the squared multiple correlation between the respective item and all others, and the internal consistency of the scale (coefficient alpha) if the respective item was deleted. Item 44 ("My partner and I use a condom when we have sex") had to be excluded from this analysis since only 10 participants responded to this question. Five items with poor discriminating power (e.g. an item-total correlation of below 0.2) on both the total scale and the theoretical sub-scales/categories were identified. These items slightly increased the Cronbach alpha of the scale/sub-scale if deleted:

1. "I would tell my parents or teacher if I was being bullied (physically or verbally) and it felt out of my control." (item-total correlation -0.79 for the total scale and -0.156 for the sub-scale).
2. "Things like eating junk food, smoking cigarettes, drinking alcohol or taking drugs help me to cope." (item-total correlation -0.203 for the total scale and -0.005 for the sub-scale).
3. "I aim to enjoy life, feel good and have fun." (item-total correlation 0.136 for the total scale and 0.195 for the sub-scale).
4. "I do things to improve my health." (for example, by exercising or eating healthy foods) (item-total correlation 0.185 for the total scale and 0.045 on the sub-scale).
5. "I rely on other people to remind me to take my ARVs." (item-total correlation 0.175 for the total scale and 0.117 for the sub-scale).

Differential item functioning (DIF) was performed to analyse for bias using cross tabulations and the Chi-square test. Individual self-management (SM) item responses were first dichotomized and then cross-tabulated according to gender and language groups. Chi-square analysis comparing language groups showed no significant differences between groups for all but two of the items. These items were "I participate in activities at school or in my community" and "I take my ARVs even if I do not want to." A larger proportion of Afrikaans home language speaking participants responded that they did not participate in activities in the community compared to the other groups and a higher proportion of isiXhosa home language speaking

participants stated that they sometimes or never took their ARVs when they did not want to. Chi-square analysis comparing gender showed no significant differences between groups.

DIF was also tested by exploring if individual items discriminated between high and low overall SM scores (calculated by grouping the lowest 25% of SM scores in one group and the highest 25% of SM scores in the other group). From the total scale, 11 items 'differentiated' between high and low total scores (i.e. there was an association between a positive/negative response on the item and a high/low total SM score) with p values of $p \leq 0.5$. These questions were:

- "I would cope if I told someone about my HIV status and that person didn't accept it or ignored me."
- "I decide by myself whom I want to tell about my HIV status."
- "I attend clinic appointments on my own."
- "I attend clinic appointments on scheduled dates."
- "I ask the doctor or nurse questions when there is anything I don't understand."
- "I tell the doctor or nurse how I am feeling."
- "I have regular contact with friends."
- "I know the names of my ARVs."
- "I know what my viral load is."
- "I know what my viral load should be."
- "Other things interfere with my plans to take ARVs."

This preliminary analysis highlighted items for exclusion or inclusion that could be explored further with a larger study sample in phase four. No items were removed at this stage due to the small sample size.

6.4 SUMMARY

In this chapter, the researcher discussed how the AdHIVSM scale was designed and pilot tested. First, the list of 55 items were reviewed by caregivers and adolescents to establish if the items were relevant and resonated with their experiences. Cognitive reasoning of participants when interrogating the items were also explored. Ten items were added to the list of items and 65 items were then reviewed by 11 experts. Experts commented on the item content validity and clarity, which resulted in refining the list of items and reducing it to 44 highly relevant items. The final list of items and other measures underwent rigorous translation into Afrikaans and isiXhosa and was piloted with 33 adolescents in the target group. Minor changes to the questionnaire were made. The following chapter concerns the validation of the developed AdHIVSM scale with a larger sample.

CHAPTER 7
ITEM ANALYSIS AND VALIDITY AND RELIABILITY TESTING OF THE INSTRUMENT

7.1 INTRODUCTION

In the fourth phase of the study, a questionnaire consisting of 11 sections, including the developed Adolescent HIV Self-Management (AdHIVSM) instrument, were administered to 385 adolescents in order to evaluate the performance of items, perform factor analysis, assess reliability, criterion-related validity and construct validity.

This chapter is detailed and presents all the sections of the questionnaire. The data is described, interpreted and displayed in frequencies and percentages or means and standard deviations as applicable. Due to the number of variables and different scales used, complete frequency tables are not included in this chapter, but are included for reference in Appendix 10. The variables used to validate the developed AdHIVSM are discussed descriptively and relationships between variables were explored where appropriate. Relevant literature is incorporated in the presentation of the results to ease the interpretation and the narrative. Descriptive statistics is followed by a description of item and factor analysis of the developed AdHIVSM measure and reliability analysis of the identified sub-scales. Hypothesis tests were executed to establish criterion-related validity and construct validity. Finally, factors influencing adolescent HIV self-management were identified using appropriate statistical tests.

7.2 DESCRIPTIVE STATISTICS

The descriptive statistics according to each section of the questionnaire are discussed. Complete frequency tables are available in Appendix 10.

7.2.1 Section 1: Background information

The background information of the participants is presented in Table 7.1a and Table 7.1b. The sample included 58.2% (n=224) females and 77.1% (n=296) participants who were isiXhosa-speaking. The median age was 15 and the interquartile range (IQR) 14-16. There were fewer adolescents aged 17 and 18 compared to the other ages.

Although most of the participants were in school, more than a third (n=138, 36.2%) had not completed the appropriate grade for their age. The correct age for a grade was determined by adding six to the grade (Republic of South Africa, 1998). Participants most frequently reported residing with their biological mother (n=151, 39.4%). One participant who reported residing with ‘other’ explained that she lived with her father and stepmother.

Table 7.1a Demographic details of participants: Questions about you

Variable	n (%)
Age [calculated from date of birth] (n=385)	
13	73 (19)
14	74 (19.2)
15	65 (16.9)
16	74 (19.2)
17	57 (14.8)
18	42 (10.9)
Home language (n=384)	
IsiXhosa	296 (77.1)
Afrikaans	53 (13.8)
English	25 (6.5)
Other	10 (2.6)
Gender (n=385)	
Male	159 (41.3)
Female	224 (58.2)
I choose not to say	2 (0.5)
With whom do you stay? (n=383)	
Biological mother	151 (39.4)
Biological father	15 (3.9)
Biological mother and father	80 (20.8)
Family member (aunt, grandmother, sister or brother, etc.)	118 (30.6)
Adoptive parents	13 (3.4)
Other	6 (1.6)
How long have you lived with this person? (n=383)	
Less than one year	31 (8.1)
1 – 5 years	37 (9.7)
6 – 10 years	37 (9.7)
More than 10 years	278 (72.6)
Level of education of primary caregiver (n=380)	
No formal schooling	15 (3.9)
Primary school	57 (15)
High school	150 (39.5)
College or university	38 (10)
Not sure / don’t know	120 (31.6)
Are you still in contact with your biological mother and father? (n=383)	
Yes, with my mother and father	131 (34.2)
Yes, only with my mother	127 (33.2)
Yes, only with my father	40 (10.4)
No	85 (22.2)

In this study 64.2% (n=246) of adolescents were living with one or both parents and 22.2% (n=85) had no contact with their biological parents. Nöstlinger, Bakeera-Kitaka, Buyze, Loos and Buvé (2015: 39) reports that 51.9% of HIV-positive adolescents in their study conducted in Kampala, Uganda and Western Kenya were living with one or both parents and that 38.8% were double orphans. In the present study, stable living arrangements of more than 10 years (n=278, 72.6%) were the most reported.

Almost half of primary caregivers were reported to have a level of education of high school or higher. The most frequent reported number of people the participants resided with in the same house was four (23.1%). Most participants had not moved in the past five years (n=163, 42.3%) and had not stayed away from home in the past week (n=268, 71.5%).

Half of the participants (n=192, 50.1%) thought they were infected with HIV at birth and many (n=159, 42.4%) reported that they found out about their status between the ages of 6 and 10 (Table 7.1b). This is contradictory to studies that indicate delayed disclosure amongst perinatally-infected adolescents (Abebe & Teferra, 2012:1097; Biadgilin et al., 2011:1; Brown et al., 2011:1053), but is supported by the qualitative data of this study. Participants who participated in the individual interviews or focus groups in phase one reported that they found out about their HIV status at a young age (around the age of nine). Some did not understand completely at that time, but their understanding increased with age. Awareness of one's HIV status was an inclusion criterion for the study and may also explain the higher percentage of early disclosure.

Those who found out about their status after the age of 12 may be perinatally-infected adolescents who were diagnosed and/or disclosed to late, or behaviourally-infected adolescents.

Table 7.1b Demographic details of participants: Questions about you

Variable	n (%)
When were you diagnosed with HIV? (n=383)	
At birth	192 (50.1)
Before the age of 6	33 (8.6)
Between 6 and 12	33 (8.6)
After the age of 12	56 (14.6)
Don't know / not sure	69 (18)
At what age did you find out you were HIV-positive? (n=375)	
Between the ages of 6 and 10	159 (42.4)
Between the ages of 10 and 12	97 (25.9)
After the age of 12	119 (31.7)

Variable	n (%)
How did you become infected with HIV? [More than one option could be selected]	
At birth/from my mother	282 (73.2)
By having sex	46 (11.9)
Forced sex or abuse	11 (2.9)
Shared needles or recreational drug equipment	8 (2.1)
Blood transfusion or other medical procedure	19 (4.9)
Don't know	94 (24.4)

The majority of adolescents thought they were infected with HIV through mother-to-child transmission (n=282, 73.2%), which is slightly higher than the number of participants who reported being diagnosed with HIV before the age of 12 (n=258, 63.3%). This indicates that some perinatally-infected participants may have been diagnosed after the age of 12. From the responses, it was clear that many participants were uncertain, since they selected more than one option and 94 (24.4%) indicated that they did not know.

Some participants (n=52, 13.5%) reported having other illnesses. Only 46 participants indicated which other illnesses they had, of which the most frequently reported was TB (n=20, 43.5%) and ADHD (n=4, 1.0%). One participant indicated 'high blood pressure', one 'depression', and one 'malaria'. Nineteen participants (41.3%) reported other illnesses, for example, an enlarged liver, a chest or ear problem, sinus infections, stiff neck, red eyes and asthma.

Responses to the questions about when they were diagnosed, how they were infected, how long they have been on ART and their risk behaviours were used to establish the most plausible route of infection. The majority of adolescents (n=344, 89.4%) appeared to have been infected either perinatally or early in life. Similarly, a study involving 10-19 year-old adolescents who live with HIV in the Eastern Cape, South Africa found that 79% of their sample were perinatally-infected. Participants were classified as perinatally-infected if they initiated ART before the age of 12 and were on ART for more than 5 years (Cluver et al., 2015:57). However, in the present study some adolescents who initiated ART recently (within the past year) were also classified as perinatally-infected since there was no other explanation for why they were HIV infected (i.e. they were not yet sexually active and did not know how they were infected). Another reason for the higher percentage of perinatally-infected adolescents in this sample may have been that behaviourally-infected adolescents were more likely to be seen with adults in the local clinic setting and therefore it was more difficult to identify them during the data collection process. Higher default rates amongst older adolescents, as reported by Maskew et al. (2016:3), may have also contributed to fewer older adolescents, who are more likely to be behaviourally-infected, to be sampled.

Very few participants (n=7, 1.8%) reported a value for their CD4 count that appeared correct. This may be because in some clinics CD4 counts are currently only requested at diagnosis and at one year on ART. Twenty participants (5.2%) selected the option in the questionnaire that their viral load was undetectable. No other participants could report a value for their viral load.

7.2.2 Section 2: Your symptoms

This section questioned the participants about symptoms experienced in the past month. The highest reported symptoms that were considered problematic to the participants (bothered them a little or a lot) were headaches (n=180, 47.8%), skin problems (n=164, 43.0%), and forgetfulness (n=161, 42.4%). Dizziness or light-headedness were also frequently reported (n=167, 43.9%). Dizziness and headaches were side-effects reported by adolescents in the qualitative data and forgetfulness was often reported by caregivers and healthcare workers. Not feeling hungry or changes in the taste of food (n=109, 28.9%) and muscle aches or joint pains (n=118, 31.1%) were the symptoms that least bothered the participants.

Most participants (n=356, 93.7%) did not report other symptoms apart from those listed in the questionnaire. Twenty-four (6.3%) indicated that they had other symptoms, for example, ‘always having a pain’, ‘feeling hopeless’, ‘asthma’, ‘ear ache’, ‘red eyes’, ‘not doing well at school’ and ‘feeling hungry all the time’. A total symptom score was calculated by summing the responses 0=’I do not have this symptom’ through 3=’It bothers me a lot’. The Cronbach alpha for the 12-item scale was 0.819. The score ranged from 0 to 33. Half of participants had a *Symptom* score between 6 (25th percentile) and 18 (75th percentile). The median score was 12.53. Figure 7.1 shows the *Symptom* score according to the gender with females having a significantly higher median score (Mann-Whitney U=17264, p=0.046).

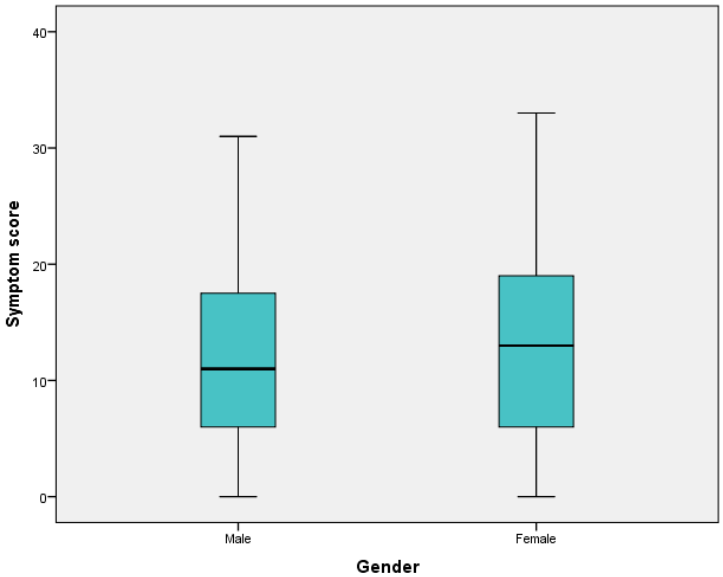

Figure 7.1 Symptom score according to gender

7.2.3 Section 3: Your treatment

Most of the participants (n=374, 97.9%) were taking treatment. One (0.3%) discontinued ART and was about to be restarted on the day he completed the questionnaire and 7 (1.8%) of the participants said that they never took ARV's. Of these, some were not yet started on ART or started ART the same day. Two participants were on ART, but when asked about it they said that the treatment was not ARVs, but for TB. Some confusion regarding the word 'ARV's' were noted since some adolescents did not seem to know the word. Caregivers used another word for ARV's in isiXhosa which when translated into English means 'breadcrumbs'.

Almost a third of participants took ARV's for more than 10 years and most (236, 62.8%) reported taking tablets once daily. Table 7.2 depicts the responses of participants regarding their treatment.

Table 7.2 Your treatment

Variable	n (%)
How long have you been taking ARVs? (n=375)	
Less than 1 year	51 (13.6)
1-5 years	66 (17.6)
6-10 years	69 (18.4)
More than 10 years	121 (32.3)
Don't know / not sure	68 (18.1)
How often do you have to take your tablets? (n=376)	
Once a day	236 (62.8)
Twice a day	121 (32.2)
More than two times a day	14 (3.7)
Don't know / not sure	5 (1.3)
When was the last time that you missed taking any of your ARVs? (n=376)	
Within the past week	117 (31.1)
1-2 weeks ago	52 (13.8)
2-4 weeks ago	14 (3.7)
1-3 months ago	20 (5.3)
More than 3 months ago	30 (8)
Never skip medication / not applicable	143 (38)
In general, over the past month, how often did you miss taking your ARVs? (n=375)	
I hardly ever take any of my ARVs	5 (1.3)
I miss most of my ARVs	14 (3.7)
I miss about half of my ARVs	17 (4.5)
I miss my ARVs a little bit of the time	171 (45.6)
I never miss any of my ARVs	168 (44.8)
How many times did you miss taking your ARVs in the last week? (n=370)	
Mean (95% Confidence interval)	1.02 (0.89; 1.16)

In the present study, higher past week non-adherence was reported compared to some studies. When asked how many times they missed a dose in the last week, only 190 (51.4%) participants reported not missing a dose within the last week. In a study by Usitalo et al. (2013:112) in the United States, 72% of youth reported not missing any doses of ARVs in the past week and in South Africa, 64% of adolescents reported complete past-week adherence (Cluver et al., 2015:57).

Less than half of the participants reported complete adherence in the two Likert scale items in this study. With the question when last a dose was missed, Usitalo et al. (2013:112) found that 28% of participants reported missing a dose in the last week (vs 31.1% in this study). With the question on general adherence over the past month, 34% said that they never missed a dose (vs 44.8% in this study). Kim, Mazenga, Yu, Ahmed and Paul et al. (2017:1) however, reported similar non-adherence amongst HIV-positive adolescents aged 12-18 in Malawi: 30% missed doses in the past week (vs 31.1% in this study); and 45% missed doses in the past month (vs 44.8% in this study). Chandwani et al. (2012:242) reported that 65.4% of youth reported complete adherence, which is higher compared to the 44.8% general past month adherence reported in the present study. Mellins, Tassiopoulos, Malee, Moscicki and Patton, et al. (2011:413) reported that 34% of participants in their sample reported recent non-adherence, which is similar to the last week non-adherence of 31.1% reported in this study.

Participants were asked to indicate their *Barriers to adherence*. The most frequent reported reasons for missing a dose of ARV's was forgetting (n=196, 52.7%), because they fell asleep or were still sleeping (n=135, 36.2%) and that taking ARVs reminded them of HIV (n=124, 33.4%). These reasons are similar to what was narrated during the qualitative interviews and focus groups as reasons for frequently missing doses. Kim et al. (2017:1) reported that the most frequent reason for missing doses reported by adolescents in Malawi was forgetting (39%). The total reasons for missing doses was calculated by adding the item codes for 0='never' through 3='often'. The Cronbach alpha of this 17-item scale was 0.837. Half of participants had a *Barriers to adherence* score of between 1 and 13 out of a maximum score of 51. Figure 7.2 shows that males had a higher median score, although the difference between males and females was not significant.

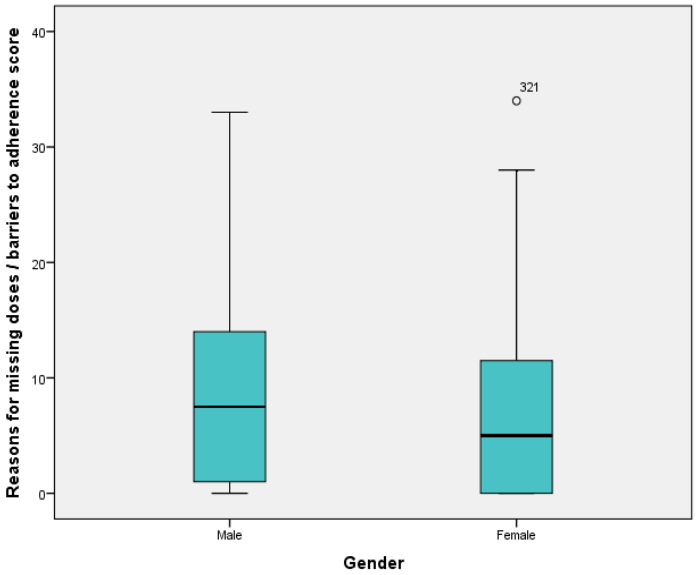

Figure 7.2 Barriers to adherence score according to gender

Fifty-five (14.3%) participants indicated that they had previously stopped their ARV's for a period of time. Of the 53 that responded to the question on how they decided to stop, 44 (83%) indicated that they stopped by themselves. The most frequent reasons for stopping treatment were that they became tired of taking the tablets or that it was too hard to take tablets every day. Other reasons included: 'feeling like I am not human'; being angry at parents for not explaining about HIV; moving to another place or visiting the Eastern Cape; feeling scared that family and friends will find out; tablets being 'disgusting', too big, too many or tasted bad; a mother that was in hospital; and a mother who did not collect medication from the clinic because she was drinking.

Treatment self-efficacy was measured on an eight-item scale of 1='not at all confident' through 10='totally confident'. The *Treatment self-efficacy* mean scores were all above 7, indicating that most participants had high treatment self-efficacy. The original 10-item scale had two components, namely integration and perseverance, but factor analysis of this eight item scale (see explanation of why two items were removed in chapter 3) indicated only one component that explained 48.3% of the variance of the scale. The Cronbach alpha of the 8 item scale was 0.843. A total *Treatment self-efficacy* score was calculated by summing the responses for the eight items. The mean was 63.16 (SD 16.6), with a minimum score of 10 and a maximum of 80.

The researcher collected data about the participant's regimen, viral load and number of missed clinic appointments from their folders. The results are depicted in Table 7.3. The regimen most often prescribed was abacavir (ABC), lamivudine (3TC) and efavirenz (EFV) which is a first-line regimen.

Table 7.3 Your treatment: Regimen, viral load and missed visits

Variable	n (%)
Current regimen (n=377)	
ABC, 3TC, EFV	132 (35)
TDF, FTC, EFV (FDC)	94 (24.9)
AZT, 3TC, LPV/r	52 (13.8)
ABC, 3TC, LPV/r	48 (12.7)
Other (7 participants or less per individual regimen)	51 (13.6)
Viral load log value (n=348)	
Median (Interquartile range)	0 (2)
Viral load (n=347)	
Suppressed (< 400)	285 (82.1)
Not suppressed (> 400)	62 (17.9)

The data obtained from patient folders indicted that 82.1% of participants who had a VL available in their folder had a suppressed viral load which is higher than the 75% reported by Usitalo et al. (2013:110), although in that study viral load was measured on the same day or within seven days of completing questionnaires which was not the case in this study. Mellins et al. (2011:416) reported that 35.7% of perinatally-infected adolescents age 10-16 had detectable viral loads in a multicentre study in the US and Puerto Rico. Viral suppression rates in the present study were, therefore, higher compared to other studies, although reported adherence was lower. This may be due to adherence and viral load not being measured at the same time in this study. The percentage of participants who were virologically suppressed were higher than the 5.2% of participants who said they had an undetectable viral load. This means that the viral load value was either not discussed with the adolescents, or more general terms may have been used by healthcare workers, for example, 'doing well', or adolescents may not have understood what was communicated. CD4 counts were not collected in they are no longer collected routinely for all patents as explained before.

Statistical analysis indicated a significant association between adherence and being virologically suppressed on the Likert scale item of when last a dose was missed ($X^2(5)=16.350$, $p=0.006$) and on the Likert scale item about general adherence over the past month (Fisher's Exact=21.469, $p<0.001$). Participants who were virologically suppressed had significantly higher *Treatment self-efficacy* levels (Mann-Whitney U=9753, $p=0.001$) and significantly lower *Barriers to adherence* levels (Mann-Whitney U=44520.5, $p<0.001$), compared to those who were unsuppressed. Further, the treatment regimen was associated with viral suppression ($X^2(3)=14.094$, $p=0.003$), indicating a higher proportion of viral suppression amongst participants on the fixed-dose combination tablet (FDC) (Table 7.4).

Table 7.4 Cross tabulation of viral suppression and treatment regimen

			Regimen				
			ABC,3TC,EFV	TDF,FTC,EFV (FDC)	AZT,3TC,LPV/r (Second line regimen)	ABC,3TC,LPV/r	Total
Suppressed < 400?	No	Count	19	4	15	10	48
		% within Regimen	15.0%	5.3%	28.8%	22.2%	16.1%
	Yes	Count	108	71	37	35	251
		% within Regimen	85.0%	94.7%	71.2%	77.8%	83.9%
Total		Count	127	75	52	45	299
		% within Regimen	100.0%	100.0%	100.0%	100.0%	100.0%

The number of tablets taken per day was associated with viral suppression: $X^2(3)=23.575$, $p<0.001$. The highest proportion of viral suppression was amongst participants who took one tablet a day (90.2%), followed by two tablets (90.1%), three tablets (78.6%) and more than three tablets (66.7%). Frequency of doses were also associated with viral suppression rates: $X^2(3)=19.878$, $p<0.001$. Participants who took doses once daily were more likely to be virologically suppressed (88.7%), followed by twice daily (73.2%) and more than twice daily (57.1%). Since participants on second line treatment are more likely not to be virologically suppressed, the abovementioned findings may be due to second line treatment requiring more tablets and more frequent treatment doses.

Most participants (n=288, 86.7%) did not miss scheduled clinic appointments; 25 (7.5%) missed one clinic appointment, and 19 (5.7%) missed more than one clinic appointment. A missed scheduled clinic appointment meant that the participant was more than two weeks late for their clinic appointment as documented in their patient folder. Kim et al. (2017:4) reported that 25.1% of adolescents in a Malawian study reported to have missed a clinic appointment in the past six months. As discussed in chapter 3, missed visits were difficult to assess since 'treatment buddies' could also collect medication on behalf of adolescents. Missed clinic appointments were therefore not used as an indicator for self-management behaviours.

7.2.4 Section 4: Your clinic or hospital

Doctors were the primary healthcare provider for most of the participants (n=241, 63.4%). Those who indicated 'other' felt that both doctors and nurses provided care to them. The overall impression of the participants was that they were always (n=301, 78.4%) or usually (n=48, 12.5%) treated with respect and that most were satisfied (n=107, 27.9%) or very satisfied (n=245, 64%) with the clinic or hospital service. Most participants enjoyed/liked attending the clinic/hospital (n=286, 74.5%).

Less than half of participants (n=177, 46.2%) reported that transport problems sometimes, usually or always prevented them from attending appointments. Maskew et al. (2016:1) reported that 32% of adolescents in Johannesburg listed high transport cost to attend clinic visits as a potential barrier to care and 61% listed the distance to the clinic as a barrier.

7.2.5 Section 5: Taking care of yourself

This section asked the participants about their self-management in the past month. The frequencies and percentages of the categories were collapsed into dichotomous responses and the items were divided in the theorised categories to ease interpretation. The mean and standard deviation of the items are reported (Table 7.5). The minimum score for each item was 1=poor self-management and the maximum score 4=good self-management. Item analysis of the developed AdHIVSM measure is discussed in section 6.3. The Cronbach alpha of the 44 item scale was 0.822 (n=108) and 0.831 for the 43 item scale (n=333) if the item on sexual behaviour was excluded.

Table 7.5 Taking care of yourself (AdHIVSM measure)

Variable	Strongly agree or Agree / Always or Most of the time	Strongly disagree or Disagree / Sometimes or Never	Mean (SD)
Knowing and understanding			
1. I know the signs and symptoms of my illness (HIV) … **(n=384)**	290 (75.5)	94 (24.5)	3.04 (0.85)
2. I can get information about HIV **(n=384)**	354 (92.2)	30 (7.8)	3.46 (0.74)
3. I know the date of my next clinic appointment **(n=384)**	352 (91.7)	32 (8.3)	3.55 (0.75)
4. I know how to contact the doctor or nurse… **(n=384)**	296 (77.1)	88 (22.9)	3.11 (0.92)
32. I understand why I am taking ARVs **(n=376)**	345 (91.8)	31 (8.2)	3.6 (0.72)
33. I know the names of the ARVs **(n=376)**	214 (56.9)	162 (43.1)	**2.73 0.98)**
34. I know at what times I should take my ARVs **(n=374)**	364 (97.3)	10 (2.7)	3.7 (0.56)
35. I know what to do when I miss the time…**(n=377)**	296 (78.5)	81 (21.5)	3.2 (0.89)
36. I understand what will happen if I don't take my… **(n=375)**	328 (87.5)	47 (12.5)	3.49 (0.81)
37. I know what my viral load is **(n=376)**	177 (47.1)	199 (52.9)	**2.53 (1.03)**
38. I know what my viral load should be **(n=376)**	201 (53.5)	175 (46.50	**2.69 (1.08)**
Believing and valuing			
5. I can achieve as much as other people… **(n=384)**	347 (90.4)	37 (9.6)	3.52 (0.78)
6. My faith helps me to stay positive… **(n=385)**	367 (95.3)	18 (4.7)	3.64 (0.63)
7. I am confident I can take care of my health **(n=385)**	362 (94.0)	23 (6.0)	3.62 (0.66)
Self-regulation			
8. I would cope if I told someone about my HIV status…**(n=384)**	198 (51.6)	186 (48.4)	**2.56 1.08)**
9. I would tell my parents or teacher… **(n=385)**	310 (80.5)	75 (19.5)	3.19 (0.94)
10. I decide by myself whom I want to tell…**(n=383)**	215 (56.1)	168 (43.9)	**2.69 (1.24)**
11. I can cope with it if people say nasty…(**n=384)**	163 (42.5)	221 (57.5)	**2.36 (1.16)**
12. Doing things I like helps me to cope **(n=384)**	330 (85.9)	54 (14.1)	3.48 (0.86)

Variable	Strongly agree or Agree / Always or Most of the time	Strongly disagree or Disagree / Sometimes or Never	Mean (SD)
13. Things like eating junk food… **(n=383) [Reverse scored item]**	52 (13.6)	331 (86.4)	3.56 (0.91)
14. I aim to be independent (taking care of myself) **(n=384)**	310 (80.7)	74 (19.3)	3.35 (1)
15. I aim to enjoy life, feel good and have fun **(n=383)**	338 (88.3)	45 (11.7)	3.58 (0.76)
16. I aim to be successful… **(n=385)**	363 (94.3)	22 (5.7)	3.75 (0.62)
17. I feel confident I can meet my health and life goals **(n=385)**	374 (90.2)	38 (9.8)	3.61 0.76)
39. I rely on other people… **(n=377) [Reverse scored item]**	122 (32.4)	255 (67.6)	**2.88 (1.15)**
40. Other things interfere…**(n=377) [Reverse scored item]**	72 (19.1)	305 (80.9)	3.3 (0.98)
41. I plan how to take my ARVs when I am not at home… **(n=362)**	244 (67.4)	118 (32.6)	3.04 1.08)
42. I aim to understand why my viral load is high or low **(n=374)**	224 (59.9)	150 (40.1)	**2.81 (1.12)**
Self-management behaviours			
18. I do things to improve my health… **(n=385)**	315 (81.8)	70 (18.2)	3.41 (0.83)
19. I attend clinic appointments on my own **(n=382)**	233 (60.9)	149 (39.1)	**2.87 (1.21)**
20. I attend clinic appointments on scheduled dates … **(n=382)**	319 (83.5)	63 (16.5)	3.44 (0.89)
21. I take part in decisions about my health…**(n=383)**	231 (60.3)	152 (39.7)	**2.86 (1.14)**
22. I ask the doctor or nurse questions when…**(n=383)**	257 (67.1)	126 (32.9)	3.1 (1.03)
23. I tell the doctor or nurse how I am feeling… **(n=382)**	264 (69.1)	118 (30.9)	3.09 (1.04)
24. I tell the doctor or nurse when I miss a dose… **(n=384)**	193 (50.3)	191 (49.7)	**2.55 (1.22)**
25. I tell the doctor or nurse about private things… **(n=383)**	136 (35.5)	247 (64.5)	**2.14 (1.25)**
43. I take my ARVs even when I don't want to… **(n=377)**	260 (68.9)	117 (31.1)	3.11 (1.18)
44. My partner and I use a condom when we have sex **(n=120)**	88 (73.3)	32 (26.7)	3.25 (1.05)
Social facilitation			
26. My family supports me to live with HIV **(n=384)**	335 (87.2)	49 (12.8)	3.59 (0.86)
27. The doctors, nurses and counsellors at the clinic… **(n=384)**	332 (86.5)	52 (13.5)	3.58 (0.81)
28. Other adolescents at the clinic support me… **(n=384)**	279 (72.6)	105 (27.3)	3.13 (1.12)
29. I have regular contact with friends… **(n=384)**	258 (67.2)	126 (32.8)	3 (1.16)
30. I participate in activities at school… **(n=385)**	239 (62.1)	146 (37.9)	**2.96 (1.12)**
31. I would find help in my community if I needed it… **(n=381)**	235 (61.7)	146 (38.3)	**2.86 (1.14)**

Self-management items that participants seemed to struggle with (items with mean scores below 3) were coping with HIV stigma (items 8, 10 and 11); participating in healthcare (item 19 and 21), communicating with healthcare providers about missing treatment or private issues (items 24 and 25); participating or finding help in the community (items 30 and 31); knowing the names of one's ARV's or one's viral load (items 33, 37, 38); showing interest in understanding one's viral load (item 42); and remembering to take treatment (not relying on other people to remind them) (item 39).

7.2.6 Section 6: Your life events

Participants had to indicate whether they experienced *Stressful Life Events* (SLEs) within the past year. From the responses it could be ascertained that many participants experienced SLEs, with 50% of participants having between two and seven SLEs in the past year. The SLEs with the highest frequencies reported was someone in the house losing their job (n=156, 40.6%), having major financial problems in the family (n=145, 37.9%), changing schools (n=133, 34.6%) and having something valuable lost or stolen (n=131, 34%). What was also concerning is that close to a third of adolescents reported personal illness and loss in the family. Given the high percentages, participants may have indicated exposure to events that did not happen within the past year only. It may, however, also indicate that HIV-positive adolescents experience a number of psychosocial challenges that puts them at risk of poor outcomes that have been reported in other studies (Petersen et al., 2010:970; Lowenthal et al., 2014:8).

Lewis, Abramowitz, Koenig, Chandwani and Orban (2015:1265) found in their study amongst HIV-infected adolescents aged 13-21 in the United States, that 47.6% reported past year exposure to violence, 37.3% changing schools and 30.1% being hospitalised. A further 31.5% reported not having enough money in the family, which is comparable with percentages reported in this study. In the present study 53 (15.3%) of participants reported being physically or verbally abused. Kim et al. (2017:4) reported that 14.6% of HIV-positive adolescents in their study in Malawi reported witnessing or experiencing violence that was significantly associated with non-adherence.

The minimum number of reported *SLEs* was 0 and the maximum 16; the median was 4 (IQR 2-6). The number of reported SLEs had a significant positive correlation with the number of reported *Symptoms* ($r=0.306$, $p<0.001$) and the *Barriers to adherence* ($r=0.307$, $p<0.001$). Further, those who were virologically suppressed reported significantly lower levels of *SLEs* (Mann Whitney $U=6609.5$, $p=0.043$). This may indicate that *SLEs* influences the general health and well-being of HIV-positive adolescents, their adherence to treatment and treatment outcomes. Males reported more SLEs compared to females as indicated in Figure 7.3 (Mann-Whitney $U=14085.5$, $p=0.05$).

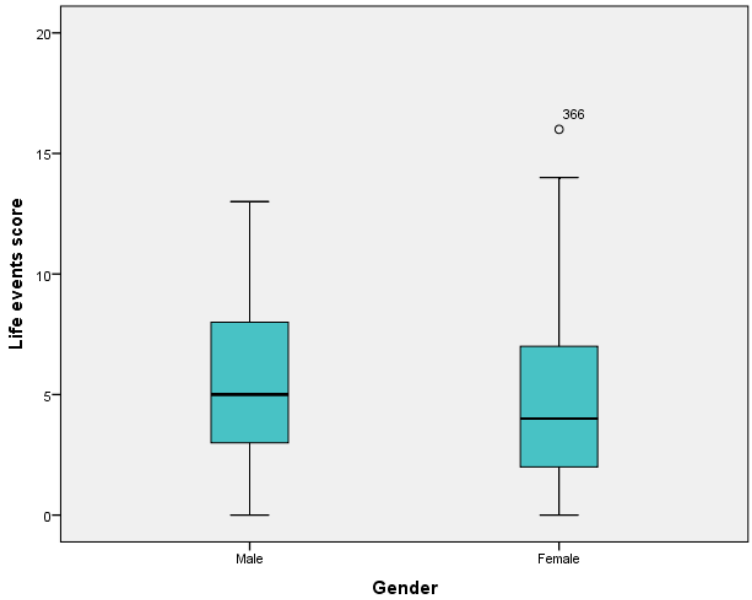

Figure 7.3 SLEs score according to gender

7.2.7 Section 7: Your quality of life

This section asked the participants about their *Health-Related Quality of Life* (HRQOL) in the past week. The sub-scale scores were converted to Rasch person parameters and international T-values as prescribed by in the KIDSCREEN Handbook (2006:82). The majority (n=354, 92.4%) of participants reported excellent, very good or good overall health. Nöstlinger, et al. (2015: 39) report that 65.4% of adolescents aged 13-17 living with HIV in their study in Kampala, Uganda, and Western Kenya reported excellent, very good or good overall health which is lower than in this study. When exploratory factor analysis (EFA) was performed on the scale, seven factors were extracted. The factors fitted the original factor structure except for the three reverse scored items on the *Mood and Feelings* (psychological wellbeing) scale and the two items related to finances on the *Family and Free Time* sub-scale, which loaded on separate factors. This could indicate that the content validity of the scale needs further exploration in the South African context.

Table 7.6 Health-Related Quality of Life (KIDSCREEN-27)

HRQOL scores	n	Cronbach alpha	Mean (SD)	Median (IQR)	Rasch person parameters Mean (SD)	T values Mean (SD)	European norms
Total HRQOL score	328	0.893	102.2 (17.6)	105 (24)			
Physical activities and health	373	0.754	17.3 (4.6)	18 (7)	0.78 (1.7)	46.98 (12.1)	46.83 (9.2)
Mood and feelings	368	0.735	27.6 (5.4)	28.5 (8)	1.5 (1.5)	48.56 (11.4)	47.3 (9.6)
Family and free time	365	0.816	24.9 (6.6)	25 (10)	0.74 (1.3)	45.79 (12.6)	48.53 (9.8)
Friends	378	0.773	14.6 (4.2)	16 (6)	1.12 (1.9)	45.63 (12.7)	50.07 (9.9)
School and learning	371	0.773	16.1 (3.4)	17 (5)	1.89 (1.8)	53.87 (11.3)	48.54 (9.2)

Currently there are no reference norms for HRQOL as measured by KIDSCREEN-27 amongst adolescents in South Africa. As depicted in Table 7.6, all the sub-scale mean scores were in the international range of 45 to 55, with standard deviations close to the international of 10 (KIDSCREEN Handbook, 2006:82). Means for *Family and Free Time* and *Friends* were slightly lower compared to international norms and the mean for *School and Learning* higher. Lower scores on the *Family and Free Time* sub-scale seemed to be related to lower ratings with regards to the availability of money, which may be due to the lower socio-economic status of the participants in this sample. In the *Friends* sub-scale, a lower percentage of participants indicated that they could always depend on friends (n=91, 23.8%), compared to always spending time with friends (n=158, 41%), having fun with friends (n=185, 48.4%) and helping each other (n=186, 48.6%). This may possibly be due to poorer quality of friendships or perhaps less closeness in friendships which have been reported in other studies (Jena, 2014:66; Petersen, 2010:973).

Nöstlinger et al. (2015: 40) used the *Family and Free Time* (Parents and home life) and *Friends* (Social support by peers) sub-scales in their study in Kampala, Uganda and Western Kenya and reports mean values of 24 (SD 5.7) and 15.6 (SD 6.2) respectively for the sub-scales, which is comparable to the mean values found in the present study. The mean for *Family and Free Time* was slightly higher in the present study and the mean for *Friends* slightly lower.

The *HRQOL* score had significant negative correlations with the number of reported *Symptoms* ($r= -0.252$, $p<0.001$), the number of *SLE's* ($r= -0.326$, $p<0.001$) and the number of reported *Barriers to adherence* ($r= -0.294$, $p<0.001$). Further, participants who were virologically suppressed had significantly higher levels of *HRQOL* compared to those who were not suppressed (Mann Whitney $U=8078$, $p<0.001$). *HRQOL* scores differed across categories of gender (Mann-Whitney $U=10530.5$, $p=0.005$) and age (Mann-Whitney $U=11595.5$, $p=0.045$), with females and older adolescents (16-18) having lower scores (Figure 7.4).

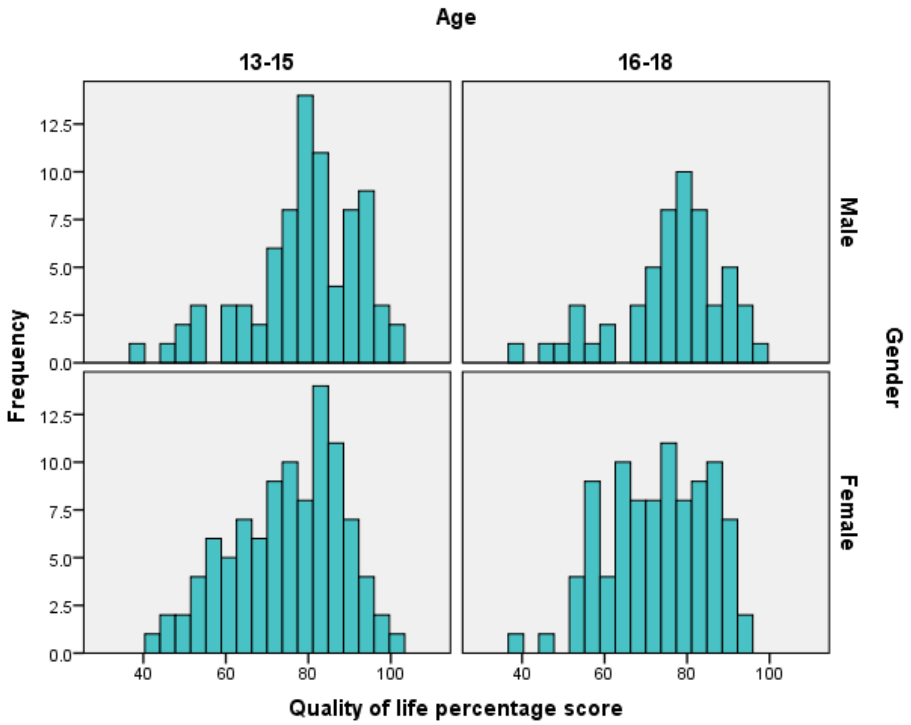

Figure 7.4 Histograms of HRQOL according to gender and age categories

7.2.8 Section 8: Your strengths and difficulties

This section focused on the participants' perceived *Strengths and Difficulties* (SDQ) in the last six months. Items were scored according to the guidelines provided by the scale developers (Youth in Mind, 2016). This scale had low internal consistency for the sub-scales and therefore only the total *Difficulties* and *Strengths* (prosocial scale) is reported. However, the Cronbach alpha for the total difficulties scale (0.657) was slightly higher than the Cronbach alpha for the youth self-report version (0.62) reported by Sharp et al. (2014:1180) that was administered to 7 to 11 year-old AIDS-orphans in the Free State, South Africa. The reason for the low reliability could have been respondent fatigue (the scale being towards the end of the questionnaire), the number of negative items in this scale, complicated wording or the limited number of response categories.

Table 7.7 Strengths and Difficulties

	n	Cronbach alpha	Mean	SD	Range
Total Difficulties score	353	0.657	12.29	5.23	29
Total Strengths (Prosocial) score	381	0.658	7.04	2.26	10

The interquartile range (IQR) of the total *Difficulties* sub-scale was six (from 9 to 15), with a minimum score of 1 and a maximum of 30 (scale range 0-40); and for the *Strengths* (prosocial behaviour) sub-scale the IQR was four (5 to 9), with a minimum of 0 and a maximum of 10

(scale range 0-10). There are currently no South African norms for the scale but the study by Sharp et al. (2014:1180) reported a mean youth self-report total *Difficulties* score of 12.31 (5.16) with a minimum score of 1 and a maximum of 35 which is very similar to this study; keeping in mind that the study population for the Sharp et al. (2014:1180) study were younger and all were AIDS orphans. Based on data available on the SDQ web page (Youth in Mind, 2016), the mean value in Australia for total *Difficulties* was 9 (5.6) and the mean value for *Strengths* (prosocial behaviour) was 8 (1.7), which shows that this study participants have more difficulties and fewer strengths compared to international norms.

When categorising the total *Difficulties* according to the guidelines of the developer, the results were as follow: Normal (n=266, 75.4%); Borderline (n=54, 15.3%) and Abnormal (n=33, 9.3%). According to the developer, categories are based on a United Kingdom population survey that showed that 80% of children scored 'normal', 10% 'borderline' and 10% 'abnormal'. This study therefore shows a lower percentage of participants categorised as 'normal' and a higher percentage categorised as 'borderline'. Difficulty scores were significantly different across home language groups, with Afrikaans-speaking participants having higher mean difficulty scores compared to other language groups (Kruskal-Wallis=8.512, p=0.014), the difference was the largest between the Afrikaans and isiXhosa groups (Adjusted p=0.022). The percentage of participants classified in each category according to the home language groups are depicted in Figure 7.5.

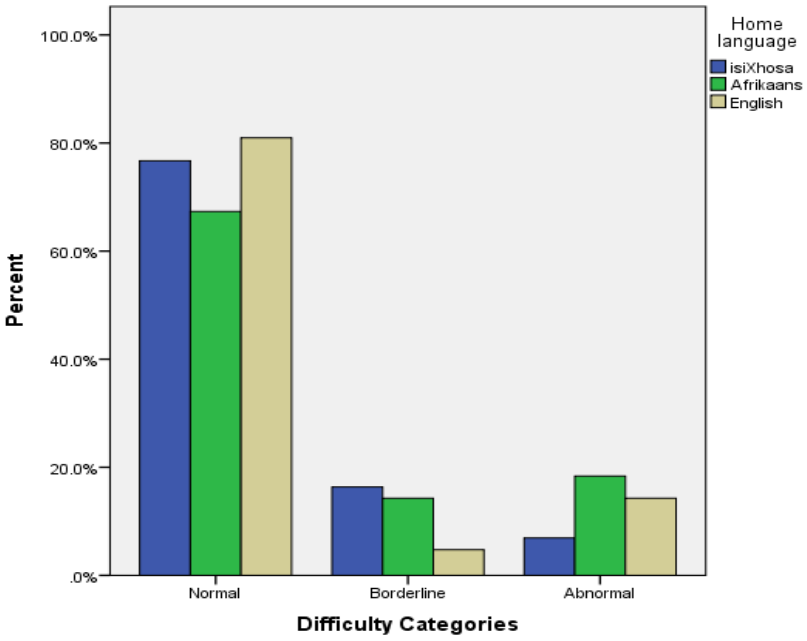

Figure 7.5 Percentage of participants classified according to difficulty categories across home language groups

A threshold *Difficulties* score of more than 17 (range 0-40) is considered predictive of mental health problems (Youth in Mind, 2016). In the present study, 73 (19%) of participants had a

threshold score > 17. A cross-sectional study amongst HIV-positive adolescents in Tanzania aged 12-24 reported a mean total *Difficulties* score of 9.9 (SD 5.6), with 13.7% having emotional behavioural threshold scores, which is lower than in this study (Dow, Turner, Shayo, Mmbaga, Cunningham & O'Donnell, 2016:825).

The total *Difficulties* score had medium positive correlations with the number of *SLEs* (r=0.466, p<0.001), *Barriers to adherence* (r=0.317, p<0.001) and the number of reported *Symptoms* (r=0.342, p<0.001). The total *Strengths* score had a medium positive correlation with *HRQOL* (r=0.357, p<0.001).

7.2.9 Section 9: Your use of alcohol and drugs

In this study 30.9% (n=116) of adolescents reported ever using alcohol (Table 7.8) which is lower than the South African national averages of 43.5-56.1% (Morojele & Ramsoomar, 2016:551), but higher than the rate of 18.5% among perinatally-infected adolescents in a study conducted in Thailand (Lee & Oberdorfer, 2009:221). In a study in the United States (US)/Porto Rico, Mellens et al. (2011:417) reported that 18% of perinatally-infected adolescents aged 10-16 reported recent substance use with alcohol the most frequently reported substance. In this study 7.2% (n=27) of participants reported using alcohol more frequently than monthly, whereas Kim et al. (2017:4) reported that 2.5% of HIV-positive 12-18 year old adolescents in a Malawian study reported using alcohol once a month or more. Fernández et al. (2015:923) reported that 21.8% of HIV-infected adolescents aged 12-24 living in the US used alcohol weekly which is much higher compared to this study and may be due to the majority of participants in their study being behaviourally-infected and also demonstrating other risk-behaviours.

Most participants in the study never used drugs such as dagga/cannabis (n=356, 95.2%) (Table 7.8). When asked if they used any other drugs, four of the six participants who indicated 'yes' specified 'cigarettes', 'dagga muffin' and 'buttons (mandrax)'. These findings may be affected by participants not wanting to acknowledge this behaviour in a questionnaire (social desirability bias). Many of the participants were perinatally-infected and it may also be that these adolescents are less likely to engage in the use of alcohol and drugs. Lee and Oberdorfer (2009:221) reported that none of the perinatally-infected participants in a study in Thailand reported drug use, whereas Fernández et al. (2015:923) reported that 28% of a sample of mostly behaviourally-infected adolescents in the US used marijuana (dagga/cannabis) weekly or daily.

Twenty-four (19.9%) of participants who used alcohol reported binge-drinking monthly, weekly or daily which is in accordance with South African national averages of binge-drinking rates of 17.9-33.5% amongst adolescents (Morojele & Ramsoomar, 2016:551).

Table 7.8 Alcohol and drug use

Use of alcohol/drugs	n (%)
How often do you have a drink containing alcohol? (n=375)	
More than 4 times per week	3 (0.8)
2-3 times per week	8 (2.1)
2-4 times per month	16 (4.3)
Once a month or less	89 (23.7)
Never	259 (69.1)
How many drinks containing alcohol do you have on a typical day when you drink? (n=125)	
1-2	61 (48.8)
3-4	19 (15.2)
5-6	22 (17.6)
7-9	11 (8.8)
10 or more	12 (9.6)
How often do you have 6 or more drinks on one occasion? (n=123)	
Never	46 (37.4)
Less than once a month	53 (43.1)
Every month	14 (11.4)
Every week	6 (4.9)
Every day or almost every day	4 (3.3)
How often have you used dagga (cannabis/marijuana) in the past 3 MONTHS? (n=374)	
Never	356 (95.2)
A few times	14 (3.7)
Every week	1 (0.3)
Every day	3 (0.8)
How often have you used tik (crystal methamphetamine) in the past 3 MONTHS? (n=373)	
Never	367 (98.4)
A few times	4 (1.1)
Every day	2 (0.5)
In the past 3 MONTHS have you ever had sex without using a condom when you were drunk or high? (n=375)	
No	90 (23.9)
Yes	14 (3.7)
Not applicable	272 (72.3)
In the past 3 MONTHS have you ever failed to perform your responsibilities (for example going to school, taking your ARVs) because you were drunk, high or hung over? (n=376)	
No	88 (23.5)
Yes	11 (2.9)
Not applicable	276 (73.6)

7.2.10 Section 10: Your sexual behaviour

Almost a third (n=121, 32%) of the participants in this group reported having vaginal sex, 26 (6.9%) anal sex and 45 (11.9%) oral sex. A study amongst perinatally-infected adolescents

older than 13 in Thailand found that only 3.7% reported sexual activity, but 35.2% reported pre-sexual activity (Lee & Oberdorfer, 2009:221). Mellens et al. (2011:417) indicated that only 17% of perinatally-infected adolescents aged 10-16 in a US/Porto Rico study reported any vaginal, oral or anal sex of which 65% reported unprotected sex. The present study included perinatally-infected and behaviourally-infected adolescents, which may be the reason for higher reported sexual activity.

The mean age of sexual debut reported by 91 participants was 14.03 (SD 2.14 and range 7-18); 38 participants indicated that they did not remember. Mellens et al. (2011:417) reported a mean age of onset of 13 years amongst perinatally-infected adolescents in a US/Porto Rico study. A notable percentage (23%) of sexually active adolescents reported multiple partners (Table 7.9) which is higher than the 12.6% reported by Shisana et al. (2014:33) in the South African National HIV Prevalence, Incidence and Behaviour Survey. In this study, less than half of the participants used condoms every time they had sex which is similar to results reported by Mhalu et al. (2013:4) and Mellens et al. (2011:416).

Seventeen (12.9%) of sexually active participants reported having a sexually transmitted infection in the past three months, nine female adolescents (12.5%) reported being pregnant at the time of questionnaire completion or being pregnant before and nine male participants (15.5%) reported to have made a woman or girl pregnant before. Sixty-four percent (n=83) of participants reported that they used a contraceptive the last time they had sex. The most frequent method of prevention reported was male condoms. A study in Uganda found a lower rate of contraceptive use amongst HIV-infected adolescents (34%), compared to HIV-negative adolescents (59%), with condoms also being the most frequently used method (Beyeza-Kashesya, Kaharuza, Eskstrom, Neema, et al., 2011:144). The rates of contraceptive use in this study is therefore much higher, which may mean that the adolescents over-reported their contraceptive use. Information related to sexual behaviour is very sensitive and participants may not have provided completely accurate information. There were options in this section for 'not applicable' and some participants may have chosen that option if they were not comfortable with answering the question.

Table 7.9 Sexual behaviour

Sexual behaviour	n (%)
In the past 3 MONTHS, how many times you had penetrative vaginal or anal sex? (n=130)	
0	31 (23.8)
1	20 (15.4)
2	26 (20)
3	17 (13.8)
More than 5	18 (13.8)
Don't know	18 (13.8)

Sexual behaviour	n (%)
Of those times in the past 3 MONTHS that you had sex, how many times did you use a condom? (n=129)	
Never	20 (15.5)
Sometimes	20 (15.5)
Almost every time	17 (13.2)
Every time	52 (40.3)
Don't know	6 (4.7)
Not applicable	14 (10.9)
In the past 3 MONTHS, how many different partners did you have vaginal or anal sex with? (n=130)	
1	59 (45.4)
2	18 (13.8)
3	7 (5.4)
More than 3	5 (3.8)
Don't know	14 (10.8)
Not applicable	27 (20.8)
How long have you been in your most recent/current main sexual relationship? (n=128)	
Less than 1 month	21 (16.4)
1-6 months	24 (18.8)
7-11 months	12 (9.4)
More than 1 year	50 (39.1)
Don't know	21 (16.4)
Did someone physically force you to have sex against your will in the past 3 MONTHS? (n=129)	
Yes	5 (3.9)
No	124 (96.1)
Did you or your partner use anything to keep from getting pregnant THE LAST TIME you had vaginal sex? (n=129)	
Yes	83 (64.3)
No	32 (24.8)
I can't remember	14 (10.9)
What did you use as prevention? (n=128)	
Male condom	94 (73.4)
Female condom	6 (4.7)
Birth control pills	2 (1.6)
Injection	9 (7.0)
Withdrawal/pull out	1 (0.8)
Not applicable	16 (12.5)
What did you use as prevention? (Second prevention method indicated) (n=4)	
Injection	5 (100)

Half of the participants who were having sex (n=65, 50.8%) indicated that they worry their partner will become HIV-positive. Participants were asked to explain their answers. Reasons for worrying included that they did not always use a condom, condoms are not completely safe or may break, because they did not know the partner's status, fear that the partner will not forgive them if he/she finds out, ruining future plans, and loving/caring for the partner.

Reasons for not worrying included always using a condom, the partner also being HIV-positive or not even thinking about HIV.

7.2.11 Section 11: How you experience stigma

Almost a third of adolescents (31.7%) said that they had never disclosed their HIV status to anyone (Table 7.10). A study conducted in Thailand found that 48.1% of perinatally-infected adolescents never disclosed their status (Lee & Oberdorfer, 2009:221) and in South Africa, a qualitative study found that over half of HIV-positive adolescents had not disclosed their status (Petersen, 2010:973). The percentage of reported disclosure in the present study may be higher since some adolescents may have understood this question to mean people knowing about their status, especially family members, and not specifically whom they had personally disclosed to. The most frequently disclosed to group were family members or relatives. More than half of the participants said that they were not treated differently after disclosing their HIV status (n=202, 54.4%).

The *HIV Stigma* scale has three subscales: *Negative self-imag*e, *Concerns about public attitudes* and *Disclosure concerns* (Wiklander et al., 2013:195). Imposing a three factor solution on this scale yielded the same factor structure that explained 71.58% of the scale variance. Adding the two additional questions (refer to chapter 3) reduced the internal consistency of the scale and was therefore excluded in the scoring.

The mean score for the 8-item scale and those of the sub-scales (except *Disclosure concerns*) were higher than the means reported by Wiklander et al. (2013:195). The total score mean reported by Wiklander et al. (2013:195) was 17.44 (SD 5.13); *Negative self-image* mean 4.33 (SD 2.16); *Public attitudes* mean 6.51 (SD 2.85); and *Disclosure concerns* mean 6.64 (SD 1.52).

Table 7.10 Disclosure and stigma

	Yes n (%)	No n (%)
Whom have you told you are HIV-positive? [Please mark all the answers that apply]		
Neighbours **(n=380)**	13 (3.4)	367 (96.6)
Friends **(n=379)**	30 (7.9)	349 (92.1)
Church community **(n=379)**	12 (3.2)	367 (96.8)
Relatives/other family members **(n=379)**	157 (41.4)	222 (58.6)
School teachers **(n=379)**	45 (11.9)	334 (88.1)
Other members of the community **(n=379)**	28 (7.4)	351 (92.6)
My sexual partner **(n=379)**	14 (3.7)	365 (96.3)
Nobody **(n=379)**	120 (31.7)	259 (68.3)

HIV stigma Scale scores	n	Cronbach alpha	Mean (SD)	Min	Max
Total score (8 items - original)	371	0.718	20.42 (4.64)	8	32
HIV stigma (Negative self-image): item 1-3	379	0.811	5.99 (2.5)	3	12
HIV stigma (Public attitudes): item 4-6	377	0.758	8.02 (7.56)	3	12
HIV stigma (Disclosure concerns): item 7-8	379	0.658	4.16 (1.66)	2	8

In the present study 77.4% (n=295) of adolescents reported that they work hard to keep their HIV status a secret, which is similar to the percentage of adolescents (77.8% of 721 participants) in a study in the Eastern Cape of South Africa that reported that they were careful about to whom they disclosed their status (Pantelic et al., 2016:11). HIV stigma has been reported in other studies in South Africa as impeding adolescents' ability to cope with their illness (Jena, 2014:53; Petersen et al., 2010:973; Cluver et al., 2013:190).

In Tanzania, 17% of HIV-positive adolescents reported "Having HIV makes me feel unclean" (vs 29.2% (n=112) in this study); 42% reported that "People I know would treat someone with HIV as an outcast" (vs 62.1% (n=237) in this study who reported "Most people with HIV are rejected when others find out") and 39% reported that "People I know think that a person with HIV is disgusting" (vs 57.8% (n=220) in this study) (Dow et al., 2016:828). The percentages of perceived stigma reported in the present study is therefore higher compared to the study in Tanzania.

In Figure 7.6 it can be seen that older adolescents had higher HIV stigma scores compared to the young adolescents (Mann-Whitney U=19326, p=0.031).

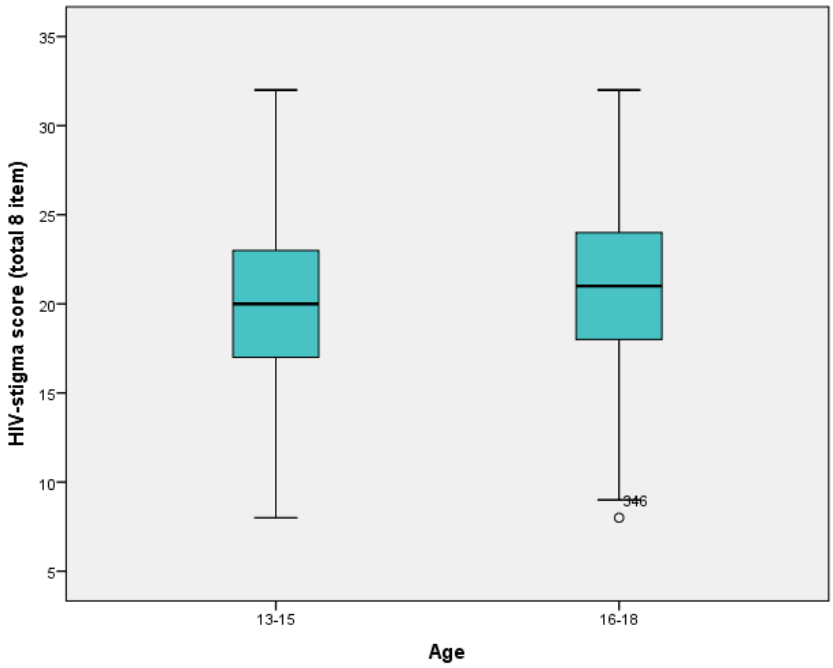

Figure 7.6 HIV stigma scores according to age category

The total *HIV Stigma* score had a medium positive correlation with total emotional and behavioural *Difficulties* (r=0.311, p<0.001) and a small negative correlation with *HRQOL* (r= -0.230, p<0.001).

7.2.12 Section12: Your resilience

CYRM-12 was used to screen for *Resilience* processes. Liebenberg, Ungar and Le Blanc (2013:131) reported a Cronbach alpha of 0.84 for the entire scale. The Cronbach alpha for this sample was slightly lower at 0.808 (n=375). There are no South-African norms for the scale and no published data. However, in personal communication with the Resilience Research Centre, quartile values from a Canadian sample (n=1596) was obtained (Brisson, 2017) (Table 7.11). From the quartile values it can be seen that the *Resilience* scores in this study were very similar to that found in Canada, with percentile values placing this study sample almost in the middle of the Canadian group with mental health/social difficulties and the Canadian 'normal' comparison group. However, the median in this sample was higher than both of the Canadian groups.

Aspects in which adolescents in the present study sample demonstrated lower resilience-resources were: having a role model/person they wanted to be like, being able to handle a situation when it does not go their way and having friends care when times are difficult. Only 37.8% (n=145) responded that they had people they wanted to be like 'a lot'; 39.8% (n=153) responded that when things do not go their way they can manage without hurting themselves or others and 174 participants (45.5%) thought their friends cared about them a lot when times are hard.

The findings may indicate that HIV-positive adolescents in this sample find it difficult to find role models to help them navigate role-clarification as reported by Kang et al. (2008:232). Further, difficulty with handling a situation when it does not go their way may indicate less resources for emotional-coping as than that reported by Petersen et al. (2010:974). Difficulty with forming close peer-relationships may have caused some participants to report that their friends do not support them in difficult times, which is congruent with other study findings (Jena, 2014:66; Petersen et al., 2010:97).

Table 7.11 Resilience

	Mean	SD	25th centile	50th centile	75th centile
Resilience score	49.25	8.56	45	52	55
Canadian sample (youth with at least two mental health/social services in past 6 months)			44	49	54
Canadian sample (comparison group)			45	51	56

Resilience had a strong positive correlation with *HRQOL* (r=0.54, p<0.001) and a medium positive correlation with total *Strengths* (r=0.417, p<0.001). There were small negative correlations between *Resilience* and *SLEs* (r= -0.271, p<0.001), total *Difficulties* (r= -0.235, p<0.001) and *HIV stigma* (r= -0.201, p<0.001).

7.3 ITEM ANALYSIS OF THE ADHIVSM

Item analysis was first performed to identify any items that could be removed from the scale before factor analysis.

7.3.1 Item-scale correlations, item variances and item means

As seen in Table 7.5 (refer to section 7.2.5), there were no items with extreme values or variances close to zero. Four items had item-scale correlations of less than 0.2 that also increased the Cronbach alpha of the scale when deleted. These items were item 13 “Doing things like eating junk food…”; 19 “I attend clinic appointments on my own”; 39 “I rely on other people to remind me…”; and 40 “Other things interfere with my plans…”. Item 13, 39 and 40 were reversed scored items and the scoring was checked, but found to be correct. Some experts concur that negative items appear to be a difficult cognitive task for younger participants since they may be confused by reversing polarities (Polit & Beck, 2017:334).

Since these items appeared to be important self-management items, a decision was made to retain the items for factor analysis. Item 44 that related to sexual behaviour, was therefore the only item removed from the scale before factor analysis since it was only answered by 120 adolescents. It may however still be an important self-management item to include in future studies.

7.4 FACTOR ANALYSIS OF THE ADHIVSM

Factor analysis was done in two phases. Firstly confirmatory factor analysis (CFA) was done to explore whether the items fitted the theoretical categories (as depicted in chapter 6). A senior statistician with expertise in structural equation modelling (SEM) performed the CFA and assisted the researcher with the interpretation. A good fit to the measurement model could not be obtained with CFA and therefore exploratory factor analysis (EFA) was performed.

7.4.1 Confirmatory Factor Analysis

Covariance-based structural equation modelling (CB-SEM) using Robust Maximum Likelihood (RML) was used to test how well the theoretical model fitted the latent structure of the variables. Further, partial least squares or variance-based structural equation modelling (PLS-

SEM) was used to determine the composite reliability and convergent validity of the constructs, as explained in chapter 3. Imputation was used to replace missing values before CB-SEM was performed.

The results of RML is illustrated in Figure 7.7. Values on the left illustrate item-variances, those in the middle factor loadings and the values on the right are the inter-factor correlations. Model-fit was assessed using the Normal Theory Weighted Least Squares Chi-square test and Root Mean Square Error of Approximation (RMSEA) (n=376).

The Chi-square was $X^2(850)=2175.12$ ($p<0.001$) and the RMSEA for the hypothesised model was 0.065 (90% CI 0.062, 0.068), $p<0.05$. The Chi-Square value evaluates the degree of discrepancy between the sample and fitted covariance matrices and should be non-significant for a good model fit. However, it is very sensitive and may reject a model with adequate specifications (Hooper, Coughlan & Mullen, 2008:54). An RMSEA value of less than 0.06 and a non-significant p value indicates a good model fit (Schmitt, 2011:310). Some literature indicates that a RMSEA of less than 0.07 is acceptable (Hooper, Coughlan & Mullen, 2008:58).

The Root Mean Square Residual (RMR) was 0.072 and the Standardized RMR 0.072. The RMR is the square root of the difference between the residuals of the sample covariance matrix and the hypothesised covariance model (Hooper, Coughlan & Mullen, 2008:54). RMR values should be less than 0.08 (Schmitt, 2011:310).

The Comparative Fit Index (CFI) was 0.80, the Goodness of Fit Index (GFI) was 0.79 and the Adjusted Goodness of Fit Index (AGFI) = 0.76. GFI shows how closely the model comes to duplicating the observed covariance matrix (Hooper, Coughlan & Mullen, 2008:54). Goodness of fit indexes of above 0.9 or 0.95 is usually indicative of an acceptable model fit (Schmitt, 2011:310).

There was therefore not an optimal model-fit for the hypothesized categories since three of the four tests to determine model-fit indicated less than acceptable values.

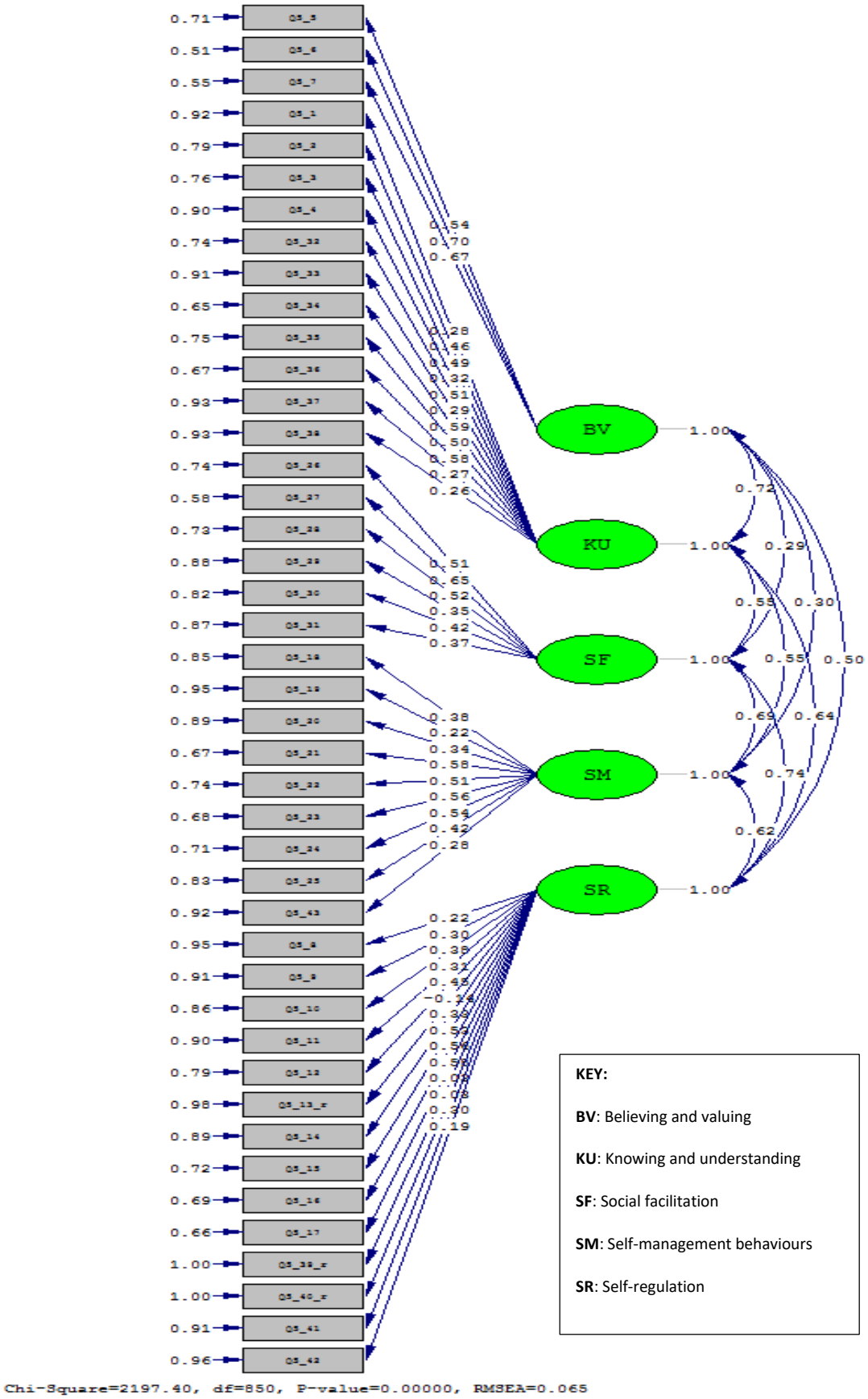

Figure 7.7 Confirmatory factor analysis measurement model

PLS-SEM was performed and yielded statistics for composite reliability, average variance extracted, discriminant validity and factor loadings. Composite reliability (CR) is a less biased estimate of reliability (Alarcón & Sánchez, 2015:5). In exploratory research, a value of 0.60 to 0.70 is considered acceptable (Hair, Ringle & Sarstedt, 2011:145). Figure 7.8 illustrates the CR of the pre-determined sub-scales, illustrating acceptable reliability, with the *Self-regulation* sub-scale demonstrating slightly lower reliability compared to the other scales.

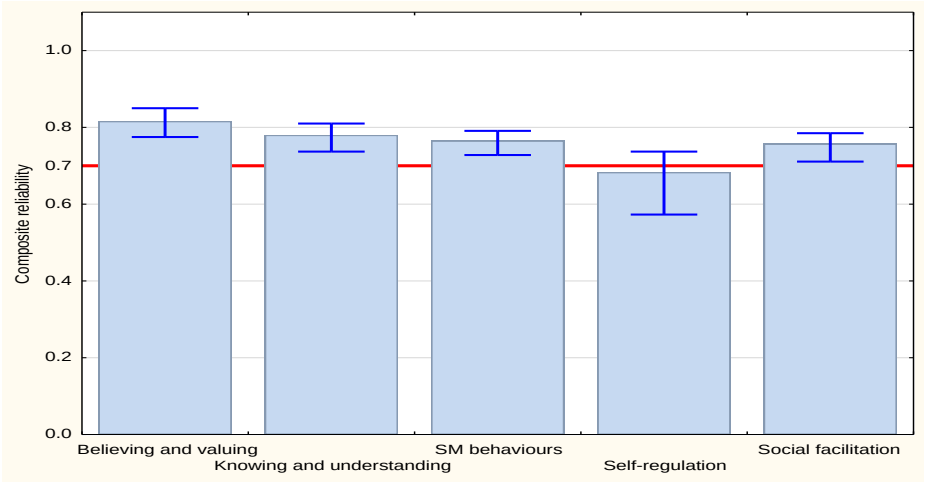

Figure 7.8 Composite reliability of sub-scales

Figure 7.9 shows the average variance (AVE) within each sub-scale captured by the construct. If the average variance extracted is less than 0.50, then the variance due to measurement error is greater than the variance due to the construct (Alarcón & Sánchez, 2015:5). However, AVE is a strict measure of convergent validity. Convergent validity means that the variables within a single factor are highly correlated. Malhotra and Dash (2011:702) note that, since AVE is a more conservative measure than CR, the researcher may conclude that the convergent validity of the construct is adequate based on acceptable CR, even though more than 50% of the variance is due to error.

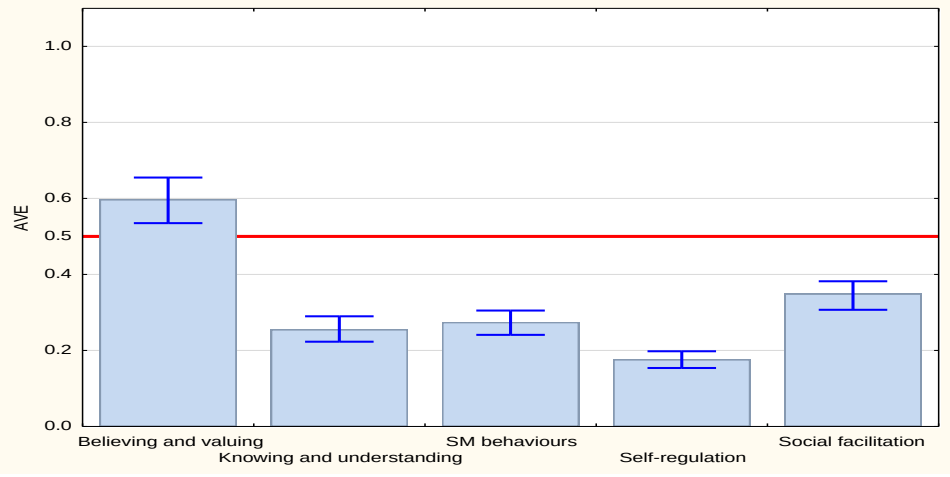

Figure 7.9 Average variance of sub-scales

Discriminant validity refers to the extent to which factors are distinct and uncorrelated. Discriminant validity was determined using the Heterotrait-Monotrait ratio that estimates whether the sub-scales were significantly different (measuring different latent variables) by comparing intra-scale correlations with inter-scale correlations. If the 95% CI includes one (1), the sub-scales are similar (Alarcón & Sánchez, 2015:5). As seen in Table 7.10, all the sub-scales were likely to measure different latent variables confirming discriminant validity.

Table 7.10 Discriminant validity

	Heterotrait-Monotrait ratio			
	1 Original Sample (O)	2 2.5%	3 97.5%	4 Discriminate
Knowing and understanding -> Believing and valuing	0.69	0.60	0.81	yes
SM behaviours -> Believing and valuing	0.35	0.25	0.49	yes
SM behaviours -> Knowing and understanding	0.64	0.54	0.74	yes
Self-regulation -> Believing and valuing	0.51	0.42	0.65	yes
Self-regulation -> Knowing and understanding	0.66	0.61	0.78	yes
Self-regulation -> SM behaviours	0.77	0.70	0.87	yes
Social facilitation -> Believing and valuing	0.29	0.19	0.46	yes
Social facilitation -> Knowing and understanding	0.55	0.46	0.68	yes
Social facilitation -> SM behaviours	0.77	0.68	0.88	yes
Social facilitation -> Self-regulation	0.72	0.62	0.85	yes

When examining factor loadings, three items did not load significantly on the pre-determined factors/categories. These items were the reverse-scored items – item 13, 39 and 40. Item 42 had a factor loading of below 0.2. The results of CFA were therefore somewhat mixed, but generally indicated that the items did not adequately fit the theoretical component structure or model. It was therefore decided to perform EFA on the items.

7.4.2 Exploratory Factor Analysis

The 43 items of the AdHIVSM measure were subjected to principal component analysis (PCA) using SPSS version 24 (IBM Corp, 2016). PCA revealed the presence of 13 components with eigenvalues exceeding one, explaining 56.86% of the total variance. An inspection of the Scree Plot (Figure 7.10) revealed a break after the first five components. Parallel analysis recommended retaining six factors (Refer to Appendix 11). However, Pallant (2016:193) mentions that the interpretation of factor analysis is more based on judgement than on statistical rules. When looking at the component matrix, 18 items had unrotated loadings of 0.4 or above on component 1; very few items loaded on the other components with only two other components with at least three items loading above 0.4. The rotated component matrix (using Varimax rotation) showed that four items loaded above 0.4 on component 1; six loaded on component 2; five loaded on component 3; four on component 4; five on component 5; seven on component 6; and less than three on the other components. It was therefore decided to explore the rotated component matrix if six, five and four factors are retained. A judgement was made based on how meaningful the components could be interpreted.

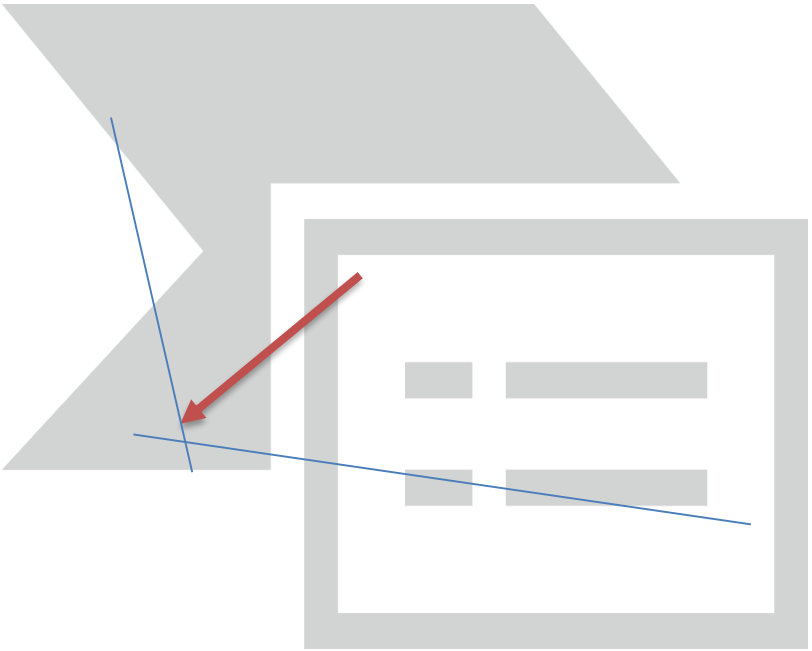

Figure 7.10 Scree plot of data

A five-factor solution yielded the most meaningful and simple component structure, explaining 34.5% of the total variance. According to Polit and Beck (2017:342), the number of factors extracted should account for at least 60% of the total variance. The low variance extracted is therefore a limitation in this study and may mean that the factors do not adequately tap the latent constructs. It may also be that a high percentage of variance are due to measurement error, for example, participants not adequately understanding the items or participant fatigue.

The identified component structure could be interpreted meaningfully using the study theoretical framework confirming face validity. Items with a factor-loading above 0.2 were considered to load on a factor. Usually an absolute value of 0.4 is preferred, but Polit and Beck (2017:344) states that smaller values can be acceptable if it makes theoretical sense. Items that loaded on more than one factor were placed under the factor that they fitted with theoretically. These items are called cross loading/complex items and can be retained if it is the latent nature of the variable (Yong & Pearce, 2013:94). Four items did not load meaningfully on any factor or did not make theoretical sense and was therefore subsequently removed: 1 “I know the signs and symptoms…”; 9 “I would tell my parents if I was being bullied…”; 39 “I rely on other people…”; and 40 “Other things interfere…”.

An additional four items lowered the internal consistency reliability of the identified sub-scales and were consequently deleted. These items include item 4 “I know how to contact the doctor.” in sub-scale 1; item 13 “Things like eating junk food…” in sub-scale 2; item 19 “I attend clinic appointments on my own” in sub-scale 3; and item 42 “I aim to understand why my viral load…” in sub-scale 4. The component and rotated component matrix with retained and unretained items are shown in Table 7.11. The final AdHIVSM scale had 35 items.

Table 7.11 Component and rotated component matrix for PCA with Varimax rotation of five factor solution of AdHIVSM items

[The colours in the Table highlights the different components identified; items not highlighted were not included in the final sub-scales]

Item	Description	Component Matrix					Rotated Component Matrix					Communalities
		1	2	3	4	5	1	2	3	4	5	
6	My faith helps me…	0.445	0.383	0.315	-0.030	0.141	**0.654**	0.108	0.110	0-.068	-0.092	0.465
7	I am confident I can take care…	0.417	0.406	0.311	0.070	0.102	**0.623**	0.132	0.095	-0.027	-0.189	0.451
5	I can achieve as much…	0.398	0.257	0.358	-0.167	0.063	**0.614**	0.020	0.037	0.003	0.067	0.384
3	I know the date of my next clinic…	0.414	0.294	0.283	-0.128	0.108	**0.591**	0.081	0.080	-0.055	0.029	0.366
34	I know at what times I should take…	0.513	0.306	0.123	-0.197	-0.171	**0.544**	0.334	-0.073	0.060	0.153	0.440
2	I can get information about HIV.	0.418	0.244	0.283	-0.039	0.027	**0.543**	0.108	0.081	0.055	-0.013	0.316
36	I understand what will happen…	0.54	0.157	0.182	-0.137	-0.125	**0.515**	0.253	0.052	0.155	0.167	0.384
32	I understand why I am taking ARVs.	0.459	0.140	0.165	-0.177	-0.173	**0.455**	0.225	-0.026	0.153	0.193	0.319
9	I would tell my parents…	0.383	0.059	0.197	-0.084	-0.010	**0.386**	0.091	0.110	0.115	0.115	0.196
4	I know how to contact the doctor…	0.327	-0.009	0.295	0.252	0.230	**0.332**	-0.063	**0.381**	0.135	-0.180	0.310
17	I feel confident I can meet…my goals.	0.516	0.262	-0.220	0.203	-0.168	0.227	**0.606**	0.119	0.092	-0.106	0.453
26	My family supports…	0.389	0.130	-0.362	0.104	-0.242	0.017	**0.599**	0.041	0.087	0.030	0.369
16	I aim to be successful…	0.459	0.390	-0.241	0.033	-0.103	0.285	**0.583**	0.020	-0.096	-0.041	0.432
27	The doctors, nurses and counsellors…	0.527	0.057	-0.305	-0.055	-0.123	0.138	**0.547**	0.159	0.046	0.215	0.392
15	I aim to enjoy life…	0.458	0.084	-0.270	0.006	-0.037	0.128	**0.473**	0.190	-0.006	0.121	0.291
12	Doing thinks I like…	0.384	0.231	-0.207	-0.075	-0.119	0.208	**0.456**	0.001	-0.049	0.098	0.263
28	Other adolescents at the clinic…	0.444	-0.087	-0.242	0.143	-0.104	0.021	**0.434**	0.258	0.179	0.084	0.294
13	Things like eating junk food…	0.060	0.529	-0.221	0.304	-0.075	0.038	**0.426**	-0.124	-0.179	-0.441	0.430
14	I aim to be independent…	0.318	-0.071	-0.275	-0.212	0.149	0.032	**0.250**	0.235	-0.161	**0.323**	0.249
21	I take part in decisions…	0.445	-0.281	-0.039	0.191	0.345	0.081	0.084	**0.639**	0.079	0.068	0.433
24	I tell the doctor or nurse when I miss…	0.393	-0.326	-0.326	-0.041	0.319	0.054	0.033	**0.572**	0.059	0.184	0.368
22	I ask the doctor or nurse…	0.417	-0.192	-0.176	0.178	0.269	0.020	0.214	**0.544**	0.020	0.057	0.346

Item	Description	Component Matrix					Rotated Component Matrix					Communalities
		1	2	3	4	5	1	2	3	4	5	
31	I would find help if I needed it…	0.373	-0.215	-0.121	0.308	0.221	-0.012	0.183	**0.542**	0.120	-0.056	0.345
25	I tell the doctor or nurse about…	0.348	-0.373	0.042	-0.051	0.321	0.081	-0.081	**0.524**	0.063	0.275	0.368
23	I tell the doctor or nurse who I feel…	0.510	-0.193	-0.131	0.075	0.023	0.101	0.307	**0.386**	0.184	0.180	0.320
18	I do things to improve my health…	0.404	0.003	-0.159	0.287	0.110	0.081	0.332	**0.384**	0.068	-0.117	0.282
19	I attend clinic appointments on my own.	0.246	-0.111	0.147	-0.103	0.371	0.231	-0.145	**0.367**	-0.105	0.151	0.243
30	I participate in activities…	0.426	-0.022	-0.127	0.205	0.097	0.117	0.307	**0.366**	0.077	-0.035	0.249
29	I have regular contact with friends.	0.321	-0.152	-0.201	0.072	0.101	-0.023	0.235	**0.332**	0.039	0.118	0.182
20	I attend clinic appointments on scheduled.	0.380	0.072	-0.135	0.107	0.125	0.155	0.294	**0.288**	-0.037	-0.011	0.195
38	I know what my viral load should be.	0.259	-0.425	0.337	0.325	-0.445	0.045	-0.017	0.102	**0.807**	-0.020	0.665
37	I know what my viral load is.	0.289	-0.377	0.325	0.409	-0.332	0.070	-0.004	0.201	**0.742**	-0.111	0.608
33	I know the names of my ARVs.	0.313	-0.196	0.271	0.134	-0.300	0.198	0.053	0.064	**0.520**	0.045	0.319
42	I aim to understand why my viral load is…	0.232	-0.365	0.021	-0.056	-0.381	-0.053	0.120	-0.002	**0.476**	0.304	0.336
35	I know what to do if I miss the time…	0.458	-0.053	0.319	-0.013	-0.104	0.428	0.059	0.148	**0.322**	0.117	0.325
39	I rely on other people to remind me…	-0.05	0.395	0.156	0.052	0.296	0.275	-0.098	0.005	-0.326	-0.286	0.273
40	Other things interfere with my plans…	-0.03	0.406	-0.048	0.358	-0.067	0.064	0.221	-0.110	-0.063	-0.441	0.301
1	I know the signs and symptoms…	0.284	-0.271	0.317	-0.112	0.024	0.252	-0.169	0.207	0.270	0.244	0.268
11	I can cope if people say hurtful things…	0.317	-0.258	-0.098	-0.380	-0.100	0.065	0.134	0.077	0.102	**0.541**	0.331
10	I decide by myself whom I want to tell…	0.376	-0.071	-0.100	-0.461	0.030	0.216	0.172	0.082	-0.092	**0.528**	0.370
43	I take my ARVs even if I don't want…	0.369	-0.092	-0.190	-0.390	-0.181	0.113	0.306	-0.020	0.045	**0.507**	0.366
41	I plan how to take my ARVs…	0.342	-0.155	-0.368	-0.161	-0.042	-0.081	0.373	0.182	-0.006	**0.354**	0.304
8	I would cope if I told someone…	0.292	-0.296	0.159	-0.130	0.106	0.158	-0.099	**0.283**	0.165	**0.290**	0.226

The five identified sub-scales are depicted in Figure 7.11 and discussed below.

Figure 7.11 AdHIVSM sub-scales

The component *Believing and knowing* included items from both the Knowing and understanding and Believing and valuing constructs identified previously. Items related to beliefs loaded stronger on this component and therefore 'Believing' was placed first.

Goals and facilitation encompassed items previously categorised under constructs of self-regulation (which included goals) and social facilitation. Item 14 "I aim to be independent" loaded stronger on component 5, but it was decided that it fitted better with component 2.

Participation included items previously categorised as self-management behaviours or social facilitation that focused on participation in care, communication with healthcare workers and participation in the community. This component could possibly also be called 'active participation/activation'. Item 20 "I attend clinic appointments on scheduled dates" also loaded stronger on component 1, but it was decided to group this under this component since it fitted better theoretically.

One component that was not previously identified was that of *HIV biomedical management*. Items in this category were specifically focused on managing the disease such as knowledge of one's viral load and the names of ARVs. The reason why this component was separated from the other knowledge items may be because the disease-specific knowledge for biomedical management such as knowledge of one's viral load is different from the knowledge necessary for daily living with HIV such as knowledge of the times tablets should be taken or a general understanding for why ARVs need to be taken.

Coping and self-regulation included a few items specific to coping with HIV stigma and taking treatment even when one does not feel like it and planning to take treatment when not at home. Item 41 "I plan how to take my ARVs…" loaded stronger on component 1, but it was decided that it was a better fit with this component.

Finally, CFA was again performed on the new structure of AdHIVSM-35. The results indicated a better model-fit than the previous model: X^2 (550)=1096.63 (p<0.001); RMSEA=0.052 (90% CI 0.047, 0.056), p=0.24; RMR=0.065; CFI=0.9 and AGFI=0.84. RMSEA had a value below 0.06, with a non-significant p value that indicates model-fit and the RMR was below 0.07. However, the goodness of fit indexes should preferably be above 0.95. The 95% confidence intervals for composite reliability (CR) of all the sub-scales were well above 0.7, except for Coping and self-regulation (CR=0.728, 95% CI 0.681, 0.757). Average variance extracted (AVE) were still below 0.5 (sub-scale values 0.282-0.48) indicating fairly high measurement error and poor convergent validity. However, as mentioned before, convergent validity can be assumed based on the CR values alone. The sub-scales had acceptable discriminant validity with no 95% confidence intervals including one. All the items had significant factor loadings on the identified sub-scales. All but four items had factor loadings above 0.4. These were items 8, 14, 20 and 35.

Intercorrelations between the sub-scales ranged from r=0.16 to r=0.6. *HIV biomedical management* had the lowest correlations with the other sub-scales. The *Participation* sub-scale had positive correlations with all of the sub-scales of between 0.35 and 0.6, which supports the theoretical framework, since this sub-scale contained several items that can be considered to be self-management behaviours/proximal self-management outcomes. The final structure identified needs further testing on a separate sample of the target population to confirm its structural validity.

7.5 RELIABILITY OF THE ADHIVSM

Reliability testing was performed on the sub-scales of the AdHIVSM-35 and the total AdHIVSM-35 following factor analysis. The internal consistency and test-retest reliability of the total 35-item scale and sub-scales are depicted in Table 7.12.

Table 7.12 Reliability of the developed AdHIVSM measure

	n	Cronbach's alpha	Test-retest Pearson Correlation coefficient	Intraclass correlation coefficient*	n	p value
Original 43 item scale	333	0.831	0.674	0.781	54	p<0.001
Final AdHIVSM-35 item scale (Total sample)	340	0.839	0.635	0.757	55	p<0.001
Age group 13 – 15	191	0.838	0.714	0.817	25	p<0.001
Age group 16 – 18	149	0.843	0.553	0.692	30	p<0.01
Questionnaire language - Xhosa	111	0.849	0.818	0.801	9	p<0.05
Questionnaire language - Afrikaans	35	0.841	0.801	0.862	9	p<0.05
Questionnaire language - English	194	0.834	0.609	0.737	37	p<0.001
Sub-scale 1: Believing and knowing (8 items)	369	0.761	0.458	0.612	60	p<0.001
Sub-scale 2: Goals and facilitation (8 items)	378	0.708	0.611	0.750	62	p<0.001

	n	Cronbach's alpha	Test-retest Pearson Correlation coefficient	Intraclass correlation coefficient*	n	p value
Sub-scale 3: Participation (10 items)	372	0.715	0.439	0.590	58	p=0.001
Sub-scale 4: HIV biomedical management (4 items)	374	0.651	0.283	0.427	60	p<0.05
Sub-scale 5: Coping and self-regulation (5 items)	360	0.547	0.567	0.727	61	p<0.001
ICC: two way mixed – Absolute agreement						

The AdHIVSM-35 had very good internal consistency reliability that was above 0.8. The reliability of sub-scales 1 to 3 was respectable, sub-scale 4 minimally acceptable and sub-scale 5 unacceptable (DeVellis, 2012:109). It may be that the components in sub-scale 4 and 5 are those adolescents struggle with more or are unsure about, therefore more variability within the sub-scale exists. It has to be kept in mind that these reliability values are inflated due to them being performed on the same data as the EFA and may be lower in a subsequent sample.

Temporal stability (test-retest reliability) was assessed by computing both Pearson's correlations and Intraclass correlation coefficients. DeVellis (2012:51) and Polit and Beck (2017:305) caution that errors in the statistical value may be due to shortcomings in the instrument as well as from the participants measured and the administration procedure. These values may have been higher if a shorter time had lapsed between consecutive administrations. The time interval should be around 1 to 2 weeks (Polit & Beck, 2017:345), but this was not practically possible in this study. The administration of the questionnaire may have also triggered some adolescents to give more thought to certain components of their care. The mean score for the AdHIVSM-35 re-test (110.89) was higher than that of the first administration (106.85). A paired-samples t-test indicated that the mean difference was significant (t= -2.521(54), p=0.015). The sub-scales *Participation* (p=0.017) and *HIV biomedical management* (p=0.047) had significant mean differences when comparing first administration and re-test mean scores that may explain their lower stability values. Further, this may mean that administration of the HIVAdolSM questionnaire in itself may assist adolescents to improve some aspects of their self-management, for example, communicating with healthcare providers and asking them to explain what their viral load is. The test-retest reliability was lower amongst older adolescents compared to younger adolescents, which may mean that the first administration of the questionnaire influenced their self-management more or that self-management is more time-sensitive in this group.

7.6 VALIDITY OF THE ADHIVSM

The developed 35-item AdHIVSM was further tested for criterion-related and construct validity. In order to compare the developed AdHIVSM-35 measure with the other variables, scores were calculated for the total scale and sub-scales.

The mean raw score of the AdHIVSM measure approximated a normal distribution (mean 111.45 (SD 13.12) and median 112 (IQR18)). The Kolmogorov-Smirnov test for normality showed no significant difference from the normal distribution (p=0.2), but the Shapiro-Wilk test showed a significant difference (p=0.001). It was therefore decided to use parametric tests, but where parametric test results differed (in terms of significance) from the non-parametric tests, it was reported in the results. The scores were converted to percentages to make interpretation easier. A histogram of the score percentages are presented below. The minimum percentage was 49 and the maximum 99. As illustrated in Figure 7.12, participants generally reported high self-management.

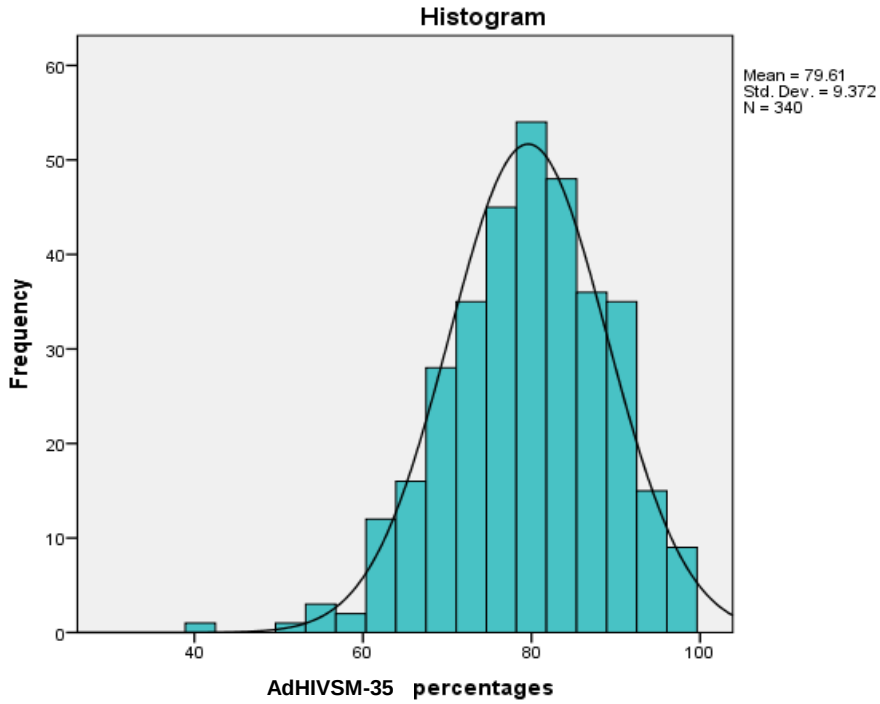

Figure 7.12 Histogram of AdolHIV-35 percentages distribution

7.6.1 Criterion-related and construct validity

Criterion-related and construct validity were assessed using hypotheses derived from the theoretical framework of the study. Pearson correlation coefficient was performed to compare the developed AdHIVSM measure with other continious variables. From Table 7.13 it can be seen that the developed AdHIVSM-35 measure and sub-scales had several significant correlations in the hypothesised directions, supporting its validity. Some of the AdHIVSM sub-scales had stronger correlations than the AdHIVSM-35 with certain variables, indicating more

shared variance. For example, sub-scale 1: *Believing and knowing*, had stronger correlations with *Barriers to adherence*, *Treatment self-efficacy*, *SLEs* and *Negative self-image*; and sub-scale 2: *Goals and facilitation* had stronger correlations with *Resilience* and total *Difficulties*. However, most of the correlations indicated a small (0.1) to medium effect (0.3).

Self-management (AdHIVSM-35) was negatively correlated with *Barriers to adherence* and the viral load log value which were both measured as continuous variables. The coefficient of determination was 6.2% for *Barriers of adherence* and 1.87% for the viral load log value, indicating that the shared variance was low.

The *Resilience* and *HRQOL* measures had correlation coefficients of medium strength with the AdHIVSM-35. The coefficient of determination was 13.61% for *Resilience* and 20.25% for *HRQOL*. Self-management negatively correlated with overall *HIV stigma* (r= -0.084), but the correlation was not significant. When exploring the stigma sub-scales, AdHIVSM-35 had significant negative correlations with *Negative self-image* (r= -0.181, p=0.001), *Disclosure concerns* (r= -0.185, p=0.001), but not with *Public attitudes concerns* (r= -0.032, p=0.561).

The sub-scale Goals and facilitation had the strongest correlations with the sub-scales of HRQOL (Table 7.14).

Table 7.13 Validity values of the developed AdHIVSM measure: Pearson correlations

	Criterion-related validity (Concurrent validity)		Hypothesis-testing construct validity (Convergent validity)							
	Barriers to adherence	Viral load log value	Treatment self-efficacy	Resilience	Health-related quality of life	Total Strengths	Stressful life events	Total Difficulties	Symptoms	HIV stigma (Negative self-image)
AdHIVSM-43	-0.271**	-0.151**	0.265**	0.428**	0.454**	0.304**	-0.087	-0.130*	-0.138*	-0.202**
AdHIVSM-35	-0.249**	-0.137*	0.220**	0.369**	0.450**	0.274**	-0.05	-0.104	-0.141*	-0.181**
Sub-scale 1: Believing and knowing	-0.308**	-0.129*	0.261**	0.336**	0.269**	0.187*	-0.153*	-0.122*	-0.111*	-0.263**
Sub-scale 2: Goals and facilitation	-0.164**	-0.126*	0.225**	0.398**	0.437**	0.290**	-0.136**	-0.155**	-0.077	-0.220**
Sub-scale 3: Participation	-0.170**	-0.040	0.095	0.289**	0.375**	0.240**	-0.029	-0.122*	-0.106*	-0.076
Sub-scale 4: HIV biomedical management	-0.138*	-0.034	0.073	0.107*	0.127*	0.661	0.046	0.033	-0.141**	-0.090
Sub-scale 5: Coping and self-regulation	-0.112*	-0.079	0.094	0.164**	0.248**	0.191*	0.054	0.005	-0.015	-0.071
***p value at 0.05 level (2-tailed) / **p value at 0.01 level (2-tailed)**										

Table 7.14 Pearson correlations of the AdHIVSM-35 sub-scales with the Health-related quality of life sub-scales

AdHIVSM-35 sub-scales	Health-related quality of life (KIDSCREEN 27) sub-scales				
	Physical activities and health	Mood and feelings	Family and free time	Friends	School and learning
Sub-scale 1: Believing and Knowing	0.223**	0.194**	0.225**	0.088	0.253**
Sub-scale 2: Goals and Facilitation	0.344**	0.243**	0.358**	0.313**	0.383**
Sub-scale 3: Participation	0.317**	0.198**	0.294**	0.266**	0.227**
Sub-scale 4: HIV biomedical management	0.171**	0.076	0.063	0.111*	0.063
Sub-scale 5: Coping and self-regulation	0.170**	0.110*	0.182**	0.207**	0.201**
***p value at 0.05 level (2-tailed) / **p value at 0.01 level (2-tailed)**					

To further test criterion validity, independent t-tests were performed to compare the mean AdHIVSM-35 scores of participants with suppressed and unsuppressed viral loads as well as those who were adherent versus those who reported some non-adherence. For adherence, the two Likert scale items assessing missed doses were recoded into adherent versus non-adherent. As shown in Table 7.15, the findings further support the criterion validity of the AdHIVSM-35. Participants who were virologically suppressed and adherent had significantly higher self-management scores. For virological suppression the effect size (Eta squared = 0.022) was small and for adherence (Eta squared=0.055) it could be considered moderate.

When analysed according to sub-scale, the *Believing and knowing* (p=0.002) and *Goals and facilitation* (p=0.041) were the only sub-scales that differentiated between virologically suppressed versus unsuppressed participants. All the sub-scales indicated significant differences across adherence categories, except the *Coping and self-regulation* sub-scale that showed no significance between groups on the Likert item 1 (when last a dose was missed) and the *HIV biomedical management* sub-scale showed no significant difference between groups on the Likert item 2 (on overage over the past month, how often do you miss taking treatment?).

Table 7.15 Independent t-tests for AdHIVSM-35 across categories of viral suppression and adherence

AdHIVSM-35	VL suppressed < 400	n	Mean	SD	T (DF)	p value
	Yes	251	80.27	9.26	2.618 (305)	0.009
	No	56	76.63	9.96		
	Adherent (Likert item 1 – last missed dose)	**n**	**Mean**	**SD**	**T (DF)**	**p value**
	Yes	130	82.43	9.04	4.435 (336)	0.00
	No	208	77.91	9.19		
	Adherent (Likert item 2 – average adherence)	**n**	**Mean**	**SD**	**T (DF)**	**p value**
	Yes	160	81.97	9.21	4.444 (336)	0.00
	No	178	77.54	9.08		

A receiver operating characteristic (ROC) curve was used to identify the cut-off point of SM that predicts viral load suppression. In ROC analysis, the area under the curve (AUC) is used as the validity parameter and should be close to 1.00, with values of 0.70 considered as evidence of adequate validity (Polit & Beck, 2017:314). The ROC analysis of AdHIVSM-35 for predicting viral suppression is shown in Figure 7.13. The curve is almost diagonal meaning that the AdHIVSM-35 does not accurately predict viral suppression (AUC 0.604). This may be due to the viral load not being measured concurrently with self-management. Further, viral

load may not be a good criterion to use, since it may not be an indicator of overall self-management, which includes social- and emotional self-management and not only medication self-management.

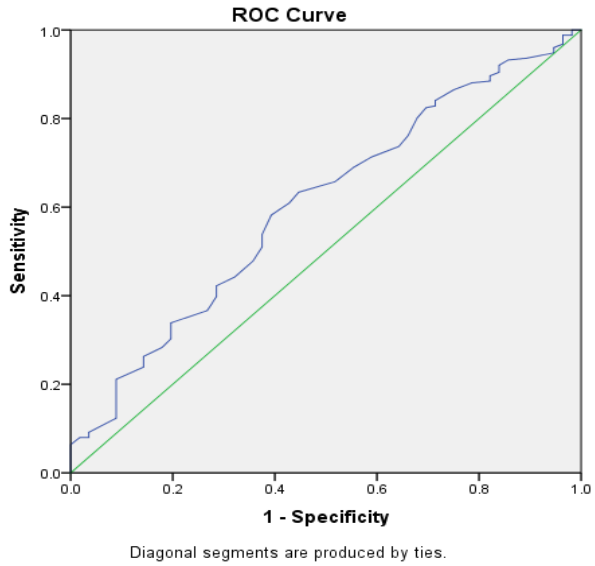

Figure 7.13 ROC analysis

In order to test for known group's validity, independent t-tests were performed to compare the mean AdHIVSM-35 scores across categories of low versus high risk behaviours. Risk behaviours were recoded to display low-risk versus high-risk. Responses such as 'I can't remember' and 'Not applicable' were excluded from the analysis. High risk groups had lower self-management scores, but the mean difference between the groups were not significant (Table 7.16), except for consistent condom use – but with a small effect size (Eta squared=0.038). When doing sub-scale analysis, participants who reported binge-drinking had significantly lower self-management scores (Mean=28.19) compared to those who did not (Mean=30.64) on the *Participation* sub-scale: t(116)= -2.097, p=0.038.

Table 7.16 Independent t-test of AdHIVSM-35 across categories of risk behaviour

AdHIVSM-35	**Alcohol use – binge-drinking**	**n**	**Mean**	**SD**	**T (DF)**	**p value**
	Yes, reports binge-drinking	67	79.23	10.05	-0.584 (106)	0.56
	No binge-drinking	41	80.33	8.46		
	Consistent condom use	**n**	**Mean**	**SD**	**T (DF)**	**p value**
	Yes, using condoms every time	46	81.15	8.59	1.947 (95)	0.054
	No, inconsistent condom use	51	77.58	9.38		
	Multiple sexual partners	**n**	**Mean**	**SD**	**T (DF)**	**p value**
	Yes, more than one partner	27	77.86	9.73	-1.187 (78)	0.239
	No, only one partner	53	80.44	8.95		

It was further determined whether AdHIVSM-35 can discriminate between groups of participants with emotional and behavioural difficulties as measured and classified by the SDQ as normal, borderline, and abnormal. No significant differences between the groups were found using one-way analysis of variance: F(2, 314)=1.036, p=0.356; although those classified as 'Normal' had slightly higher self-management scores (Mean=80.05, n=241), followed by 'Borderline' (Mean=78.77, n=47) and 'Abnormal' (Mean=77.67, n=27) (Figure 7.14). When sub-scales were explored, groups significantly differed on the *Goals and facilitation* sub-scale: F(2,344)=3.614, p=0.028, with those classified as normal having higher mean scores, followed by borderline and abnormal.

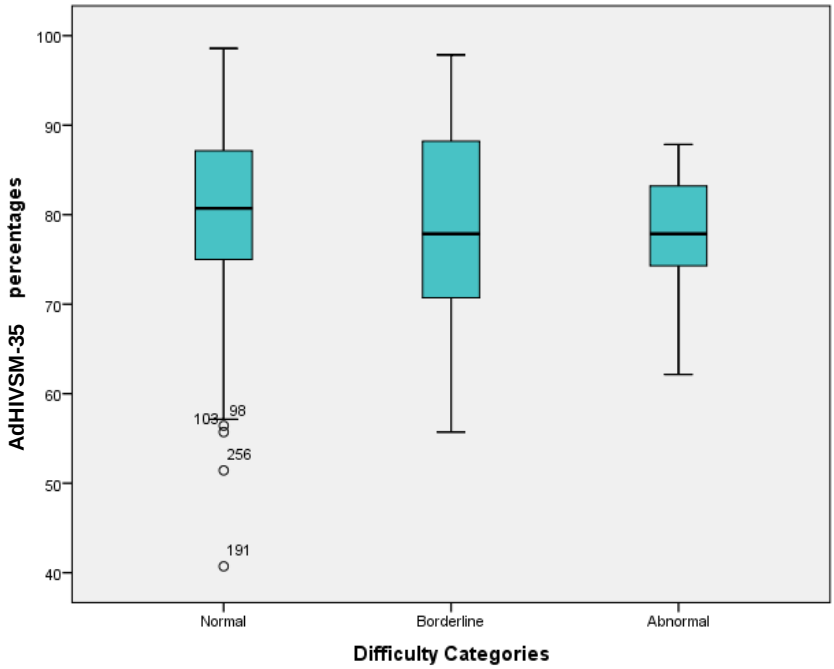

Figure 7.14 Boxplot of AdHIVSM-35 across categories of difficulty

The hypothesis tests and decisions are summarised in Table 7.17. Overall the hypotheses tests supported the validity of the measure, except for the relationship of AdHIVSM and *SLEs* and total *Difficulties*. It may be that SLEs only influence certain components of self-management. For example, *SLEs* did not correlate with the total AdHIVSM-35 scale, but it did have significant negative correlations with two sub-scales: *Believing and knowing*; and *Goals and facilitation*. Similarly, total *Difficulties* did not have a significant correlation with total AdHIVSM-35, but it did correlate significantly with three sub-scales, with the *Goals and facilitation* sub-scale showing the strongest correlation.

It must be noted that although most of the null hypotheses were rejected, effect sizes were generally small to medium. This may be due to the limitations of using self-report measures, social desirability bias, the characteristics of the individual participants (for example, variability in their reasoning when answering questions and different literacy levels), and the lack of

available measures, that comprehensively captures the components of adolescent HIV self-management, to adequately assess criterion and convergent validity. Although the sub-scales *HIV biomedical management* and *Coping and self-regulation* showed weak correlations with other variables, it may be because none of the other measures captured the latent variables contained in these sub-scales. The sub-scales identified with the EFA should still be confirmed with CFA in a subsequent sample and therefore these results must be interpreted with caution.

Table 7.17 Null hypotheses for testing validity and decisions

	Null hypotheses	p value of test	Decision
1	Participants who are virologically suppressed do not have higher self-management compared to those who are not suppressed.	0.009	Reject
2	Participants who are adherent to treatment do not have higher self-management compared to those who are non-adherent.	<0.001	Reject
3	Treatment self-efficacy is not positively associated with self-management.	<0.001	Reject
4	Resilience is not positively associated with self-management.	<0.001	Reject
5	Self-management is not positively associated with health-related quality of life.	<0.001	Reject
6	Behavioural and emotional strengths is not positively associated with self-management.	<0.001	Reject
7	Stressful life events is not negatively associated with self-management.	0.372	Retain
8	Behavioural and emotional difficulties is not negatively associated with self-management.	0.065	Retain
9	Reported symptoms is not negatively associated with self-management.	0.012	Reject
10	Experiencing stigma (negative self-image and disclosure concerns) is not negatively associated with self-management.	0.001	Reject
11	Participants who report risk behaviours (inconsistent condom use) do not have lower self-management compared to those who do not report risk behaviours.	0.054	Reject
12	Self-management is the same across categories of behavioural and emotional difficulties.	0.356	Retain

7.7 FACTORS INFLUENCING SELF-MANAGEMENT

Contextual factors that may influence self-management were subsequently explored by doing appropriate statistical inferential tests using the identified AdHIVSM-35 and sub-scales.

7.7.1 Questionnaire administration method and language

There were no significant differences in self-management scores when comparing the method of questionnaire administration: $F(2,337)=1.640$, $p=0.196$. However, there were differences identified on the *Goals and facilitation* ($p=0.002$) and *HIV Biomedical management* sub-scales ($p=0.023$). Participants ($n=45$ and $n=43$ respectively) who completed the questionnaire with a fieldworker had a slightly higher mean score on the *Goals and facilitation* sub-scale and a

slightly lower mean score on the *HIV biomedical management* sub-scale compared to the other methods of completion.

Concerning questionnaire language, one-way analysis of variance indicated no significant difference between the groups F(2,337)=2.375, p=0.095), although participants who completed isiXhosa questionnaires tended to have lower mean percentage scores (78.11, n=111) compared to those who completed English (80.52, n=192) or Afrikaans questionnaires (79.31, n=35). Significant differences were detected in the *Goals and facilitation* (Afrikaans having the lowest mean) and *Coping and self-regulation* (isiXhosa having the lowest mean) sub-scales. It is not clear if the sub-scale differences can be attributed to the method of administration and questionnaire language only or if it may have been due to other demographical factors.

7.7.2 Individual and family factors

The distribution of AdHIVSM-35 differed according to the highest grade that was completed F(7,327)=2.036, p=0.05). Participants who completed grade 12 had the highest mean score (86.52) and participants who indicated they completed grade 8 had the lowest mean score (76.54). The boxplot below (Figure 7.15) shows the distribution of scores according to the grades.

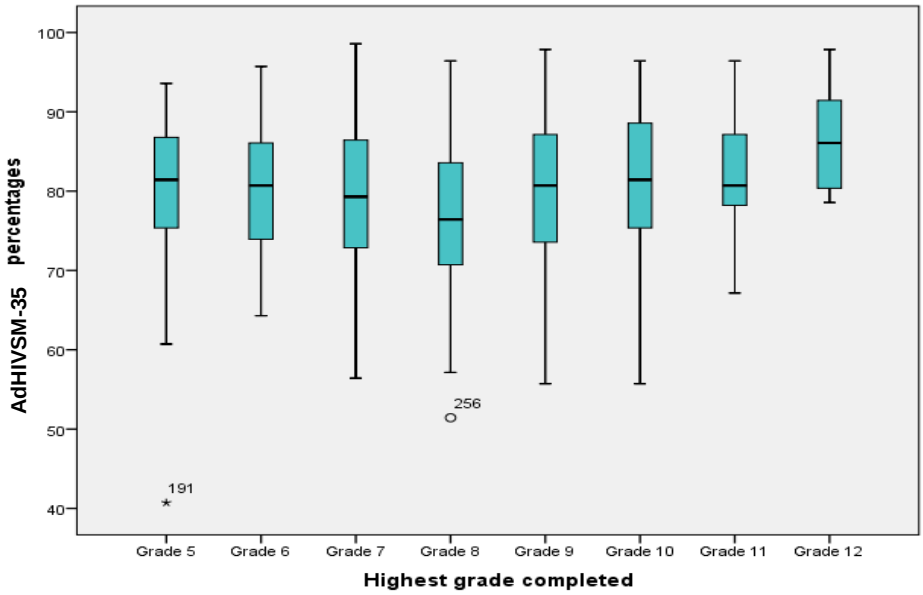

Figure 7.15 Boxplot of AdHIVSM-35 across categories of highest grade completed

It is not clear why self-management was lower in the group that indicated they completed grade 8. When looking at the AdHIVSM35 scores according to age (Figure 7.16), a similar pattern is seen as mean scores for the age categories increase from 13 (78.08, n=67), 14

(79.78, n=65) to 15 (82.15, n=59), drop at age 16 (77.78, n=64), and then steadily increase again at 17 (80.09, n=49) and 18 (80.56, n=36). The differences were, however, not significant.

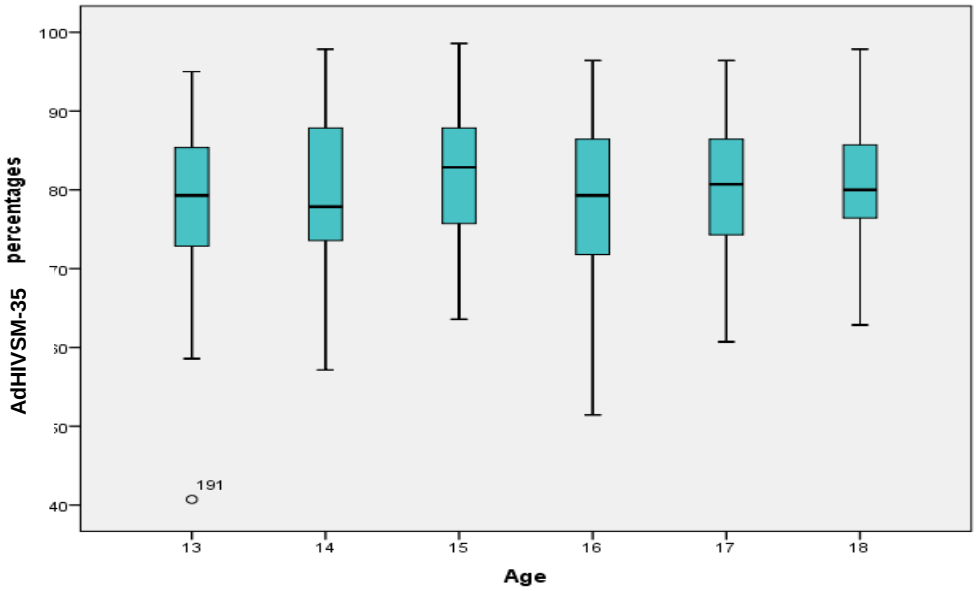

Figure 7.16 Boxplot of AdHIVSM-35 across categories of age

There were no significant difference in self-management scores between participants who were in the correct grade for their age and those who were not: t(335)=0.888, p=0.375.

Scores for each of the sub-scales based on gender, age and home language are depicted in Table 7.18. Only the *Goals and facilitation* sub-scale had significant differences between groups according to home language, with the mean the lowest amongst Afrikaans-speaking participants.

Table 7.18 AdHIVSM-35 mean raw scores according to gender, age and language

Scale	Gender			Age			Home Language			
	Male	Female	p value	13 – 15	16 – 18	p value	Afrikaans	English	Xhosa	p value
AdHIVSM-35	n=137	n=201	**0.146**	n=191	n=149	**0.490**	n=45	n=23	n=262	**0.682**
Mean (SD)	112.71 (12.6)	110.59 (13.4)		111.88 (13.2)	110 (13.1)		112.24 (13.6)	113.13 (13.6)	111.05 (13.04)	
Sub-scale 1: Believing and Knowing	n=149	n=218	**0.620**	n=205	n=164	**0.283**	n=51	n=25	n=282	**0.479**
Mean (SD)	28.50 (3.3)	28.68 (3.4)		28.83 (3.4)	28.36 (3.8)		28.55 (3.2)	27.88 (4.8)	28.73 (3.3)	
Sub-scale 2: Goals and Facilitation	n=154	n=222	**0.886**	n=208	n=170	**0.158**	n=53	n=24	n=290	**0.037**
Mean (SD)	28.14 (3.8)	28.08 (4.05)		28.36 (3.8)	27.78 (4.1)		27.21 (3.86)	29.71 (2.8)	28.09 (4.1)	

	Gender			Age			Home Language			
Scale	**Male**	**Female**	**p value**	**13 – 15**	**16 – 18**	**p value**	**Afrikaans**	**English**	**Xhosa**	**p value**
Sub-scale 3: Participation	n=153	n=217	**0.138**	n=207	n=165	**0.153**	n=50	n=24	n=287	**0.425**
Mean (SD)	30.01 (5.4)	29.11 (6.01)		29.87 (5.6)	29.01 (5.9)		30.40 (5.8)	28.83 (5.9)	29.34 (5.7)	
Sub-scale 4: HIV biomedical management	n=154	n=218	**0.295**	n=206	n=168	**0.290**	n=52	n=25	n=286	**0.196**
Mean (SD)	11.32 (2.8)	11.02 (2.7)		11.30 (2.9)	10.99 (2.6)		11.63 (2.8)	11.68 (3.2)	11 (2.7)	
Sub-scale 5: Coping and self-regulation	n=147	n=211	**0.321**	n=201	n=159	**0.219**	n=48	n=24	n=278	**0.296**
Mean (SD)	13.93 (3.3)	13.61 (3.45)		13.52 (3.5)	13.97 (3.3)		14.27 (3.0)	14.17 (3.1)	13.53 (3.5)	

With regard to family background information, self-management scores did not differ across categories of primary caregiver: $F(5,333)=0.471$, $p=0.798$; or length of stay with primary caregiver: $F(3,335)=1.380$, $p=0.249$). Mean self-management scores did, however, differ between categories in the *Goals and facilitation* sub-scale ($p=0.026$), with those indicating that they stayed for more than 10 years with a caregiver having higher mean scores compared to the other categories.

One-way analysis of variance showed no differences between categories of level of education of primary caregiver ($F(4,332)=0.165$, $p=0.956$) or whether participants were still in contact with their biological parents ($F(3,335)=1.591$, $p=0.191$).

The mean self-management score was higher for participants who indicated that they had not moved in the past five years compared to those who indicated that they had moved, although scores did not decrease in a linear way as frequency of moving increased ($F(6,325)=2.429$, $p=0.026$). The only sub-scale in which differences were significant was the *Believing and knowing* sub-scale. The non-parametric Kruskal-Wallis test was not significant except on the *Believing and knowing* sub-scale.

There were no significant correlations between the self-management scores and the number of nights stayed away from home in the past week ($r= -0.104$, $p=0.059$) or the number of family members in the house ($r= -0.021$, $p=0.713$). Both correlations were negative, indicating that more people in the house and staying nights away from home may influence self-management negatively. When exploring associations between the sub-scales and the number of nights stayed away from home in the past week, significant negative correlations were found with the *Believing and knowing* ($p=0.006$) and the *Goals and facilitation* ($p=0.026$) sub-scales.

7.7.3 Illness and treatment related factors

Self-management significantly differed across categories for when participants were diagnosed with HIV ($F(4,333)=2.837$, $p=0.024$); those who indicated that they were diagnosed between the age of 6 and 12 had the highest mean self-management score. Sub-scale analysis showed higher mean self-management scores for the *Goals and facilitation* sub-scale for participants who indicated that they were diagnosed at birth ($p=0.004$). There were no specific trends to explain the findings and the non-parametric Kruskal-Wallis test did not indicate a significant difference between groups except on the *Goals and facilitation* sub-scale.

Self-management did not differ across categories of when the participant found out about their HIV status ($F(2,330)=0.027$, $p=0.973$) or whether they had other health conditions ($t(317)= -0.435$, $p=0.664$).

With regards to route of infection, those participants who indicated that they did not know how they were infected had significantly lower self-management scores compared to those who knew ($t(115.15)= -2.299$, $p=0.023$), specifically on the *Believing and knowing* ($p<0.001$) and *Goals and facilitation* ($p=0.008$) sub-scales. Not knowing by which route they were infected with HIV (which could be an indicator of lack of communication at home about HIV or being in denial) may negatively influence adolescents' HIV self-management.

Those who were perinatally-infected did not differ from those who were behaviourally-infected with regards to self-management scores ($p=0.989$). However, sub-scale analysis revealed that behaviourally-infected adolescents had significantly higher self-management scores on the *Believing and knowing* ($p=0.02$) and *Coping and self-regulation* ($p=0.033$) sub-scales.

There was a significant difference between groups according to how long participants had been taking ART ($F(4,332)=4.468$, $p=0.002$). Those who had been taking ART for more than 10 years had higher self-management scores compared to the other groups, but with no linear trend, for example, scores did not decrease as the length of treatment decreased. Subscales *Knowing and believing* ($p=0.013$); *Goals and facilitation* ($p=0.001$); and *Coping and self-regulation* ($p=0.002$) showed significant differences between groups, but with no specific trends.

The number of tablets taken every day was not associated with self-management ($F(4,330)=0.971$, $p=0.424$), although the sub-scale for *Believing and knowing* showed a significant difference ($p=0.034$) between those who take three tablets (mean=27.88) and those who take one tablet (mean=29.44) per day.

The frequency of taking tablets was significantly associated with self-management scores ($F(3,335)=3.381$, $p=0.019$). Those who take tablets once daily had higher self-management

scores compared to those who did not know or those who take more than once daily doses. The sub-scales *Believing and knowing* (p=0.001) and *Goals and facilitation* (p=0.019) indicated differences across categories, both showing higher self-management with once daily doses.

7.7.4 Healthcare context factors

Healthcare context variables that showed a significant difference between response categories were whether the healthcare provider treated participants with respect (F(3,336)=5.60, p=0.001), satisfaction with services (F(3,334)=8.538, p<0.001), whether they enjoyed/liked coming to the clinic (t(337)=2.265, p=0.024) and whether they experienced transport problems (F(3,334)=3.867, p=0.010).

Those who indicated that they were always treated with respect had the highest mean self-management scores, and mean values showed a downward trend, through to 'never' with the lowest mean. The subscales for *Goals and facilitation* (p<0.001) and *Participation* (p=0.001) showed significant differences across categories following the same trend in mean scores. The effect size (Eta squared) for being treated with respect was 0.048, indicating a small effect.

Satisfaction with services showed a similar trend in mean scores; the highest being 'very satisfied' and the lowest mean score being 'very dissatisfied'. The subscales *Believing and knowing* (p<0.001), *Goals and facilitation* (p<0.001) and *Participatio*n (p=0.011) showed the same trend. The effect size (Eta squared) for satisfaction was 0.071, indicating a moderate effect.

Participants who enjoyed coming to the clinic/hospital had higher mean self-management scores (mean=80.33) compared to those who did not like coming (mean=77.72). Only the sub-scale for *HIV biomedical management* showed a significant difference across groups (p=0.004), also indicating a higher score in those who liked coming to the clinic. The Eta squared was 0.015 indicating a small effect.

Participants who never had transport problems had higher self-management scores compared to the other response options, but with no linear trend noticed. Subscales that showed significant differences across groups were *Believing and knowing* (p=0.002); *Goals and facilitation* (p=0.004) and *Participation* (p=0.030), but no trends were observed.

The type of provider, whether a doctor or nurse did not influence self-management scores (t(328)= - 1.093, p=0.233).

Figure 7.17 illustrates the relationships between variables explored in this study according to the IFSMT. The arrows merely indicates that a relationship exists, but does not assume cause and effect. For the purpose of the Logic Model, the AdHIVSM component of *Participation* is included as a self-management process. It can however also be viewed as a proximal outcome of self-management processes, since it contains items that portrays self-management behaviours.

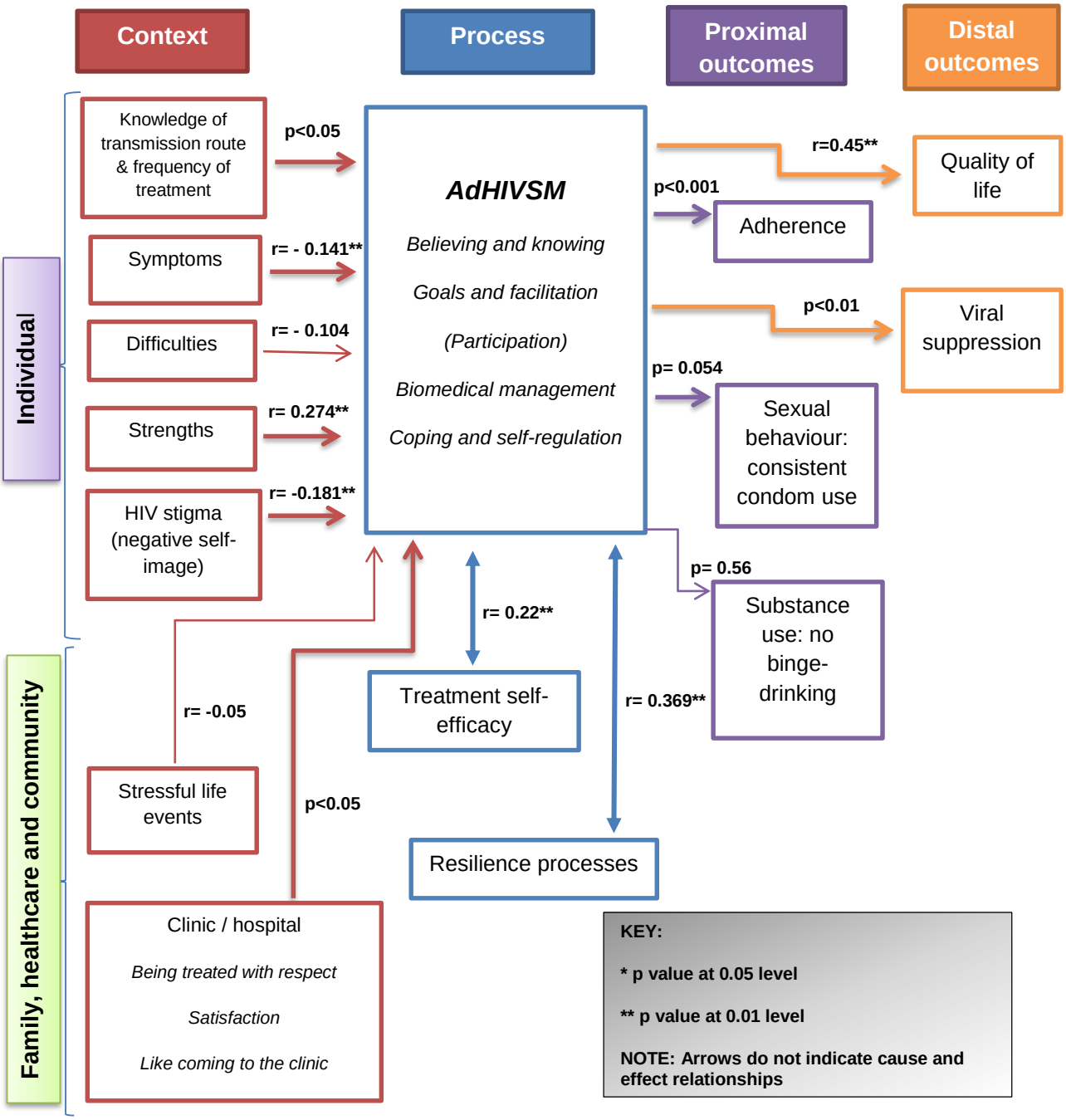

Figure 7.17 Logic Model based on study results according to the IFSMT

7.8 DISCUSSION OF KEY RESULTS

The sample of adolescents included in this study were mainly isiXhosa-speaking and perinatally-infected. There was a fairly even spread across gender and age categories, but with fewer 17 and 18 year-olds. Most adolescents were in school but 36.2% were not in the correct grade for their age. A trend noticed was that self-management was lower for the age group 16 years or those who indicated they had completed grade 8 compared to the other age and grade categories. It may indicate that middle adolescence is a period where adolescents become increasingly aware of their social environment and stigma associated with the illness and is supported by the evidence that older adolescents (16-18) had significantly higher HIV stigma scores. Older adolescents may also be in a period where they transition from being dependent on their caregivers for SM to becoming more independent. Keough et al. (2011:486) found that collaboration with parents decreased and problem-solving skills increased from early adolescence through to late adolescence amongst adolescents living with diabetes. Overall, younger adolescents (13-15) had higher mean scores on the SM sub-scales compared to older adolescents (16-18), except for the *Coping and self-regulation* sub-scale. These mean differences were not significant. It may, however, indicate slightly better coping and self-regulation skills amongst older adolescents and further research is needed to explore the relationship between age and self-management.

Primary caregivers included biological parents, family members and adoptive parents, with 39.4% residing with their biological mother followed by 30.6% living with a family member. Most participants (72.6%) indicated that they lived with the person who looked after them for more than 10 years, 34.2% were still in contact with their mothers and fathers and 22.2% had no contact with their biological parents. Surprisingly, family contexual variables did not significantly influence overall SM, although stability in terms of living with one caregiver for a long period, not changing houses and not staying away from the house appeared to positively influence the *Believing and knowing*, and *Goals and facilitation* sub-scales. It may, therefore, be the quality of the relationships within the family context and good family functioning rather than merely the physical family arrangements, that positively or negatively affects SM (Grey et al., 2006:280). Socio-economic status (SES) was not assessed in this study and therefore the influence of SES on SM could not be determined.

In this sample, just over half of the participants indicated that they were infected at birth and 42.4% indicated that they became aware of their HIV status before the age of 10. As previously mentioned, it appeared that a higher percentage of adolescents in the present study became aware of their HIV status at an early age compared to other studies (Abebe & Teferra, 2012:1097; Biadgilin et al., 2011:1; Brown et al., 2011:1053). Almost a quarter (24.4%) of participants indicated that they were not sure how they were infected with HIV and was

associated with lower self-management. Since awareness of their HIV status was an inclusion criteria for this study, the influence of non-disclosure on SM could not be assessed. However, the association between the knowledge of transmission route and SM may mean that disclosure alone does not positively influence SM, but illness-related knowledge following disclosure that is reinforced through communication with caregivers and healthcare providers does (Barnes et al., 2013:314).

Very few participants indicated that they had other chronic illnesses (13.5%) of which the most reported other illness was tuberculosis. The mean *Symptom* score was 12.53 (7.64) out of a maximum score of 36, with skin problems, headaches and forgetfulness the most frequently reported. *Symptoms* were significantly negatively correlated with self-management although the correlation was weak, indicating that it may only have a small effect on overall self-management. Since most of the adolescents in the present study did well on treatment and were generally healthy, the symptoms, especially skin problems, could also be related to physiological and hormonal changes of adolescence and not attributed to HIV. Some symptoms mentioned, for example, headaches and dizziness were reported by adolescents as side-effects in the qualitative phase of the study. Further, forgetfulness was frequently mentioned by caregivers and healthcare workers as a major challenge. The reported *Symptoms* had a moderate negative correlation with the *Mood and Feelings* sub-scale of the *HRQOL* measure ($r= -0.306$, $p<0.001$), which indicates that more symptoms may negatively affect the psychological well-being of participants or vice versa.

Most participants (32.3%) indicated that they had been on treatment for more than 10 years and either took tablets once daily (62.8%) or twice daily (32.2%). The most frequently prescribed regimen was ABC, 3TC and EFV (35%), followed by TDF, FTC, EFV (fixed dose combination) (24.9%), which indicates that most of the participants were still on first line treatment. Taking tablets only once daily was significantly associated with higher self-management, which is congruent with findings by Cox et al. (2014:136) that a more complex treatment regimen is a barrier to self-management. Overall adherence was generally slightly lower as reported other studies (Usitalo et al., 2014:112; Mellins et al., 2011:413; Chandwani et al., 2012:242), with between 38% and 51.4% of participants indicating that they never miss their treatment on the three adherence questions. *Barriers to adherence* had a mean of 7.78 (7.6) out of a maximum score of 51 indicating that there may not be so many barriers to adherence in this group. The most frequent reported reasons for missing any doses were forgetting (n=196, 52.67%), falling asleep or were still sleeping (n=135, 36.1%) and that taking ARVs reminded them of HIV (n=124, 33.4%). *Barriers to adherence* were negatively correlated ($r= -0.249$) with self-management although the correlation coefficient indicated a small effect. Webel et al. (2012:6) found a small positive correlation of $r=0.18$ between ART adherence and self-management amongst women who live with HIV. Correlations between

the dicotomised Likert scale adherence items and AdolHIVSM-35 were slightly stronger at r=0.235 and r=0.236.

Treatment self-efficacy scores were generally high with mean scores above 7 (out of 10). *Treatment self-efficacy* was positively correlated with self-management although the strength of the relationship was small. Since self-efficacy is considered to be central to or associated with self-management (Bodenheimer et al., 2002:2496), this lends support for the developed AdHIVSM-35. The low percentage of shared variance (4.8%), may be explained by the fact that the self-efficacy measured was only related to treatment-taking behaviours whereas AdHIVSM-35 covered more constructs. This may to some extent support the discriminant validy of the instrument. Webel et al. (2012:6) found small to medium positive correlations of r=0.26-0.34 between chronic disease self-efficacy and their developed self-management measure sub-scales amongst women who live with HIV. As reported by Johnson et al. (2007:360), higher treatment self-efficacy was associated with being adherent and virologically suppressed in this study.

Viral loads collected from patient folders indicated that 82.1% of the participants were virologically suppressed with a viral load less than 400 copies/ml, which is higher compared to other studies (Usitalo et al., 2014:112; Mellins et al., 2011:413). Those participants who were adherent to treatment and virologically suppressed had significantly higher overall self-management levels but the effect sizes was small. In our study self-management negatively correlated with the viral load log value (r= -0.137). Schilling et al. (2009:232) similarly found small negative correlations (r= -0.1 to -0.26) between self-management sub-scales and HbA1c levels amongst adolescents with diabetes in their study. Ryan and Sawin (2009:219) consider treatment adherence to be a self-management (SM) behaviour. Treatment outcomes such as viral suppression are distal outcomes of SM. The results of the study therefore support the association between SM processes (AdHIVSM-35), SM behaviours (treatment adherence) and SM outcomes (viral suppression) although no causal relationships can be inferred.

A high proportion of participants (79.4%) indicated that they were always treated with respect by their healthcare provider, 64% were very satisfied with services and 74.5% enjoyed coming to the clinic. Just over half of the participants (53.8%) indicated that transport problems never prevented them from coming to the clinic. Analysis showed that being treated with respect may have a small effect on self-management, whereas satisfaction with services may have a medium effect on self-management. This supports the notion that healthcare system factors incluence SM (Schulman-Green et al., 2012:140; Modi et al., 2012:479).

Self-management percentage scores had a high mean of 79.61 (9.37), indicating overall high self-management amongst participants. Areas where lower scores were observed included

coping with disclosure and stigma, participating in decisions and in community activities, communicating about sensitive issues such as missing a dose of ART or private issues, knowledge of one's viral load and names of ARVs, and relying on other people to remind one to take ARVs.

Half of the participants reported between two and seven *SLEs* in the last year. Experiencing *SLEs* was negatively correlated with self-management, but the association was not significant, except on the *Believing and knowing* (r= -0.153, p<0.01) and *Goals and facilitation* sub-scales (r= -0.136, p<0.01) . It had a moderate negative correlation with *HRQOL* and had the strongest negataive correlation with the *Mood and Feelings* sub-scale (r= -0.377, p<0.001). *SLEs* may adversely affect socio-emotional coping of adolescents who live with HIV (Petersen et al., 2010:970; Lowenthal et al., 2014:8). As reported by Corless et al. (2013:478), the total number of *SLEs* also correlated positively with the number of reported *Symptoms* and *Barriers to adherence* in this study.

Reported *HRQOL* was generally high and comparable to European norms. The *Family and Free Time* and *Friends* domains had lower means compared to European norms. Two items related to finances in the *Family and Free Time* sub-scale had lower ratings which may be due to the lower socio-economic status of the participants. Lower reported rates of being able to depend on friends may indicate less deep friendships (Petersen, 2010:973). In the *School and Learning* domain, a higher mean was reported which is suprising given the high percentage of adolescents who were not in the correct grade for their age. *HRQOL* had a medium positive correlation with self-management. The *Goals and facilitation* AdHIVSM sub-scale had a medium positive correaltion with the *School and Learning* HRQOL sub-scale (r=0.383) and the *Participation* AdHIVSM sub-scale had a medium positive correlation with the *Physical Activities and Health* HRQOL sub-scale (r=0.317). This may indicate that schools may still be a resource that can positively influence AdHIVSM. Further, the theoretical framework of Ryan and Sawin (2009:219) places *HRQOL* as a distal outcome of SM processes. The association between SM and *HRQOL* therefore supports this framework.

Mean scores on the SDQ scale were similar to another South African study on younger AIDS-orphans (Sharp et al., 2014:1174). When *Difficulty* scores were classified, 75.4% of participants were categorised as normal, 15.3% as borderline and 9.3% as abnormal. The number of reported *Difficulties* were higher and the number of *Strengths* lower compared to other international studies and norms (Youth in Mind, 2016; Dow et al., 2016:825). Emotional and behaviours *Strengths* (the prosocial scale) positively correlated with self-management, but with a small effect. There was a negative correlation between emotional and behavioural *Difficulties* and self-management, but the p value was not significant. Similarly, self-management mean scores did not differ significantly across the difficulty categories, although

a trend could be observed – those who were classified as normal had higher mean self-management scores. Total *Difficulties* had a medium positive correlation with the number of *SLEs* (r=0.466) and total *Strengths* had a medium positive correlation with *HRQOL* (r=0.357).

A number of adolescents (30.9%) reported using alcohol, 4.8% using dagga (cannabis) and 1.6% using tik (crystal methamphetamine). Reported substance use was higher in this study compared to studies amongst perinatally-infected adolescents (Lee & Oberdorfer, 2009:221; Mellens et al., 2011:417; Kim et al., 2017:4), but lower compared to studies amongst primarily behaviourally-infected adolescents (Fernández et al., 2015:923). Those who reported binge-drinking as measured by drinking more than six drinks on one occasion, had lower self-management scores although the difference in means were not significant. Almost a third (32%) of participants reported ever having vaginal sex and 6.9% reported anal sex. The mean age for sexual debut was 14.03 (2.14). Risky behaviours such as daily/weekly/monthly bindge drinking (19.6%), inconsistent condom use (44.2%) and multiple partners (23%) were reported. Further, 12.9% of adolescents who were sexually active had a STI in the past three months. Participants who reported consistent condom use had significantly higher self-management scores and participants who reported having more than one partner in the past three months also had lower self-management scores, but the mean difference was not significant. Sexual behaviour could also be considered a self-management behaviour that is influenced by SM processes. The results, therefore, provide some support for the theoretical framework (Ryan & Sawin, 2009:219).

Almost a third of adolescents (31.7%) had not disclosed their HIV status to anyone which is congruent with low disclosure rates reported in other studies (Lee & Oberdorfer, 2009:221; Petersen et al., 2010:973). Mean *HIV stigma* scores were generally high (Mean=20.42, SD=4.64, out of a maximum score of 32) when compared with other studies (Wiklander et al., 2013:195; Dow et al., 2016:828). The *HIV stigma* sub-scales, *Negative self-image* and *Disclosure concerns,* had negative correlations with self-management, but with a relatively small effect. The SM sub-scales *Believing and knowing* and *Goals and facilitation* had the strongest negative correlations with *Negative self-image* (r= -0.263 and r= -0.220). *HIV stigma* levels had a medium positive correlation with emotional and behavioural *Difficulties* (r=0.311) which may mean that the inability to cope with HIV stigma may result in emotional and behavioural difficulties amongst HIV-positive adolescents as reported by Petersen et al. (2010:973).

Resilience scores in this group were generally high and comparable with median values from a Canadian sample. Items that indicated lower resilience included having people you want to be like, being able to fix things when it does not go your way, knowing that your friends care about you, and liking how the community celebrates. Although no empirical study could be

found that investigated the relationship between self-management and resilience, it was deduced from the literature that resilience and SM are closely-related. Resilience and SM may draw on similar protective resources on an individual, family and community level (Theron & Theron, 2010:8). The study findings support this notion and shows that *Resilience* has a medium positive correlation (r=0.450) with self-management.

Item analysis and factor analysis, including confirmatory and exploratory factor analysis were performed on the developed AdHIVSM items. Confirmatory factor analysis did not show an optimal model-fit with the initial theoretical categories. Exploratory factor analysis was then performed and five components identified: *Believing and knowing*; *Goals and facilitation*; *Participation*; *HIV biomedical management* and *Coping and self-regulation*. Most of the sub-scales had adequate reliability values and validity testing revealed associations in the hypothesised directions. The results indicate support for the reliability and validity of the developed measure although it is noted that the associations had small to medium effect sizes. Confirmatory factor analysis on the identified sub-scales through another study is needed to confirm the identified component structure.

7.9 SUMMARY

In this chapter, the results of the fouth study phase were presented. First, the results were displayed and discussed descriptively to provide background information about the study sample and describe the participants' responses to the questionnaire sections, as well as the reliability of the scales where applicable. Secondly, factor analysis was performed and included CFA on the theoretical structure followed by EFA, which resulted in a final 35-item scale with five-components. Thirdly, reliability and validity of the components were assessed that generally indicated acceptable results. Finally, factors influencing self-management were investigated using appropriate statistical tests. In the next chapter, the final discussion, key findings and recommendations follow.

CHAPTER 8
DISCUSSION, KEY FINDINGS AND RECOMMENDATIONS

8.1 INTRODUCTION

In this chapter, the research findings are discussed according to the research questions stated at the onset of the study. It was thought to be more meaningful to discuss the research findings according to the research questions rather than the objectives in order to reflect both the qualitative and quantitative research processes and capture meta-inferences. Meta-inferences or integrated inferences are shared understandings about the phenomenon derived from qualitative and quantitative data analysis (Tashakkori & Newman, 2010:514). With sequential mixed-method designs, the second round of data collection is rooted in the first. In the context of instrument development, subjecting themes that arise from qualitative analysis to further quantitative analysis such as exploratory factor analysis yields meta-themes (Onwuegbuzie et al., 2010:67). In this study, items and components inductively developed from the qualitative data and literature were subjected to Exploratory Factor Analysis (EFA) in the fourth phase of the study, which yielded components that could be meaningfully explained by the theoretical framework and are supported by the qualitative data. The components of the developed AdHIVSM can, therefore, be called meta-inferences or meta-themes. Further, findings from the qualitative and quantitative data are integrated in the discussion in order to provide a comprehensive description of the phenomenon. The principles applied to ensure the validity and quality of the findings and inferences of the mixed-method approach are discussed in chapter 3 (section 3.7).

The discussion of the study findings as it relates to each of the research questions is followed by a reflection on the instrument design process, limitations, key findings and recommendations.

8.2 DISCUSSION

The overall aim was to explore the nature and healthcare needs of adolescents living with HIV around self-management, in order to develop and psychometrically evaluate a measurement instrument that incorporates contextual-, cultural- and developmental-specific aspects of adolescent HIV self-management in a South African setting.

8.2.1 Research question 1: In a South African context: how is adolescent HIV self-management realised?

In this study, a definition for self-management was developed that takes into consideration the context, culture and level of development of adolescents who live with HIV. This broad

definition is described in chapter 6 and states that self-management is the processes and behaviours adolescents who live with HIV engage in to take care of their chronic illness with the assistance of their caregivers, health workers, family, friends, peers and educators. The components of AdHIVSM identified in chapter 6 changed slightly following the exploratory factor analysis conducted in the fourth phase of the study. These components consist of processes/behaviours such as *Believing and knowing*; *Goals and facilitation*; *Participation*; *HIV biomedical management*; and *Coping and self-regulation*. Figure 8.1 provides a graphic illustration of the components of adolescent HIV self-management in a South African context. Participation is placed in the bottom centre, since it contains components that can be viewed as self-management behaviours or proximal self-management outcomes as described in the Individual and Family Self-Management Theory (IFSMT) of Ryan and Sawin (2009:217). Arrows do not assume a cause and effect relationship. The coefficient of determination indicates the shared variance between the components and was calculated based on the correlations between the components found with Confirmatory Factor Analysis (CFA). Only the relationships with the strongest shared variance are indicated.

Figure 8.1 Components of adolescent HIV self-management in a South African context

It can be seen that the components of *Believing and knowing* and *Goals and facilitation* have 36% shared variance. *Goals and facilitation* further has 32% shared variance with *Coping and self-regulation* and 36% shared variance with *Participation*. *Coping and self-regulation* has 34% shared variance with *Participation*. The *Goals and facilitation* component has the

strongest correlations with the other components, meaning that it is a key component of adolescent HIV self-management. It was also the most stable AdHIVSM component as it had the highest test-retest reliability. It may further lend support for the assertion of Bronfenbrenner in his Bioecological Model that proximal processes (microsystem interactions between the individual, their family and the health services) is central to adolescent development or in this context, self-management (Rosa & Tudge, 2013:251).

Table 8.1 portrays the AdHIVSM components and a summary of the key attributes of each component. This is followed by an in-depth discussion of each of the components.

Table 8.1 AdHIVSM components with key attributes

Component	Key attributes
Believing and knowing	Views or ideas about one's illness, the future and confidence to self-manage. Awareness and comprehension of how to navigate the healthcare system and the importance of treatment (ARVs).
Goals and facilitation	Internal- and external motivation for self-management in the form of setting individual goals and support by family, healthcare workers, peers and friends to take care of one's health.
Participation	Being actively involved in one's healthcare and in the community.
HIV biomedical management	Knowledge of and motivation to understand whether one is doing well on treatment or not.
Coping and self-regulation	Managing HIV stigma, making decisions about disclosure and integrating taking treatment into one's daily routine.

Believing and knowing concerns adolescents' beliefs and knowledge about their illness. It is a combination of the components *Knowing and understanding* and *Believing and valuing* identified through the qualitative data. Ryan and Sawin (2009:217) also grouped these two concepts together in their theory. From the definitions discussed in chapter 6, *Knowing and understanding* entails an awareness and comprehension of one's disease, treatment regimen, accessing the healthcare system and what constitutes healthy behaviour. *Believing and valuing* are views or ideas about how adolescents see themselves, living with the disease presently and in the future; including what they consider important or beneficial and the expected outcomes of treatment or health behaviours. Schulman-Green et al. (2012:136), in their self-management framework that was based on a meta-synthesis of studies, refers to a

concept they name “illness needs” that involves aspects such as learning, taking ownership of health needs and performing health promotion tasks.

The items in this sub-scale involved adolescents’ beliefs that they can achieve the same goals as other people who do not have HIV and being confident that they can take care of their own health. This relates to the need of adolescents to feel normal, the process of accepting one’s HIV status and making sense of one’s identity. The qualitative data revealed that although perinatally-infected adolescents felt that being HIV-infected was unfair to them, most had some sense of control, since their illness could be managed through taking ARVs. The quantitative responses indicated that 70.1% of participants strongly agreed that they could take care of their own health, but only 65.4% of participants strongly agreed that they could achieve as much as other people who do not have HIV. Drawing on faith to give hope for the future was a key aspect identified that loaded the strongest on this component and 70.4% of adolescents strongly agreed with this statement. ‘Faith’ in this context could imply believing in or finding hope in God or ancestors, but as revealed through the qualitative data, it could also be a belief or hope that there will be a cure for HIV in the future. Adolescents need to know where to get information about their illness should they need to, why they are taking ARV’s and the consequences if they do not take their treatment every day. On a practical level, they need to know at what time they should take treatment and what the date of their next appointment at the clinic or hospital is. This information was mostly provided in the healthcare context by healthcare providers. From the qualitative narratives, it was apparent that not all adolescents understood the implications of living with HIV. The quantitative data indicated that 24.5% of adolescents did not know the signs and symptoms of their illness. They were more likely to know why they need to take ARVs and when to take their ARVs, as 70% and 73.5% of participants respectively strongly agreed with these statements. A lower percentage of adolescents (63.5%) strongly agreed that they understood what will happen if they did not take their treatment every day. This supports the qualitative assertions that some adolescents may lack insight into their illness and have not taken ownership yet. The mean percentage score for *Believing and knowing* was 89.42% (SD 10.69).

Beliefs and disease-specific knowledge are closely related concepts, as identified in this study. Positive beliefs may create space for knowledge-acquisition. From the qualitative data it appeared that both beliefs and knowledge are strongly situated within the family and healthcare (microsystem) context and that it is influenced by interactions with caregivers, healthcare workers and peers. Positive beliefs and disease-specific knowledge are acquired through repetitive interactions with key persons (proximal processes) influencing the adolescent. Open discussions about HIV at home and optimistic caregiver and family attitudes seemed to facilitate this process. Cox et al. (2014:131) and Grey et al. (2006:280) reported

that interactions within the family and effective communication facilitates self-management and promotes better health outcomes.

The Cronbach alpha of this sub-scale was 0.76 indicating good internal consistency. It correlated stronger than the 35-item AdHIVSM and the other sub-scales with *Barriers to adherence*, *Treatment Self-efficacy* and *HIV stigma* (*Negative self-image*). This means that positive beliefs and more knowledge about the illness may be associated with better treatment self-efficacy, better self-image and less perceived barriers to adherence. Cluver et al. (2015:S57) and Modi et al. (2012:478) also commented that beliefs about a positive future is an important motivator for treatment adherence and self-management. The ICC used to measure test-retest reliability for the sub-scale was 0.612 which was minimally acceptable and indicated adequate stability of this component.

Since *Believing and knowing* seemed to be connected with interactions with caregivers and healthcare providers, it was expected that there will be associations between family background and healthcare factors and the *Believing and knowing* sub-scale. Family background factors that influenced *Believing and knowing* processes were moving to a new house in the past five years and staying nights away from home. It appeared that stability in terms of not moving to a new house and not staying nights away was associated with higher mean *Believing and knowing* scores. As mentioned before, the quality of family interactions appeared to be more apparent in influencing self-management than the persons with whom the adolescent resides. The *Believing and knowing* sub-scale had the highest positive correlations with the *Family and Free Time* and the *School and Learning* sub-scales of the HRQOL scale, which may mean that beliefs and knowledge is not only influenced by the family but also by the school context. Theron and Theron (2010:2) found that schools are a resource that can foster resilience, although Mburu et al. (2014:9) found that schools are not a good support resource due to HIV stigma. Similarly, the qualitative data of this study indicated a high prevalence of HIV stigma in schools. Yet, the quantitative data may point towards a perception of good relationships at school that foster self-management. On the *Resilience* scale, 66.1% of participants responded that they felt they belonged at their school ‘a lot’ and a further 16% selected that they belonged ‘quite a bit’. Higher scores for the *Believing and knowing* sub-scale was also associated with knowing by which route one was infected, taking fewer tablets and a lower frequency of taking doses of treatment. Participants who were more satisfied with healthcare services were also more likely to have higher *Believing and knowing* levels. Less complicated regimens and positive interactions with healthcare workers have been identified as factors facilitating self-management (Cox et al., 2015:130; Schulman-Green et al., 2012:140).

Goals and facilitation include aspects of internal and external motivation to take care of one's health. Setting goals was categorised under self-regulation in chapter 6, but from the quantitative analyses it appeared to be more closely related to social facilitation. Social facilitation as defined in chapter 6, are processes that occur within the relationships they have with caregivers, family, health workers, friends, peers and educators. Ryan and Sawin (2009:217) states that social facilitation includes social influence, emotional-, informational- and instrumental support and negotiated collaboration. They further state that social facilitation enhances the capacity of the individual to change. It may be that the meaningful interactions with significant role players or the feeling that one is supported, enables adolescents to become motivated internally and have positive life goals. The qualitative findings indicated that adolescents appreciated the support from their family and some even said that it made them feel happy and healthy.

In this sub-scale, internal motivation is realised through goals such as aiming to be successful, enjoying life and being independent. This should further be accompanied by confidence that one has the ability to reach these goals and by active positive coping strategies such as doing things they like, which may in itself provide further motivation. In this study, 80.7% of adolescents aimed to be independent, 88.3% aimed to enjoy life and 94.3% aimed to be successful. The majority of adolescents (90.2%) felt confident that they could reach their goals. This supports the qualitative data that revealed that HIV-positive adolescents have general goals such as studying further or having a career. Externally, adolescents are motivated by support from family, healthcare workers and other adolescents at the clinic that facilitates their ability to self-manage. The quantitative data indicated that 78.1% of participants strongly agreed that their family supported them, 75.3% strongly felt that the healthcare workers supported them and 55.5% reported that other peers at the clinic truly supported them. The lower percentage of perceived peer support may be because some of the healthcare facilities included in the fourth phase of the study did not have peer support groups. Further, not all adolescents attending HIV services at facilities with peer support groups were in a group. Participants who attended peer support groups and those who did not attend peer support groups were included in the sample. Adolescents who did not attend peer groups may have had less interaction with peers. The greatest source of support for adolescents is therefore the immediate family and is supported by the qualitative data. The mean percentage score for *Goals and facilitation* was 87.81% (SD 12.38).

The Cronbach alpha of this sub-scale was 0.708. It had stronger positive correlations with *Resilience* and total *Strengths* and a stronger negative correlation with total *Difficulties* compared to the total AdHIVSM-35 and other sub-scales. This may mean that resources for resilience and resources for self-management co-vary or are similar in nature. According to Theron and Theron (2010:2), supportive family relations enable adaptation in the context of

HIV/AIDS. Adolescents with more emotional and behavioural *Strengths* and fewer *Difficulties* had higher *Goals and facilitation* scores in this study. Modi et al. (2012:476) states that behavioural and emotional problems negatively affect self-management. The ICC for this component was 0.75 indicating acceptable test-retest reliability and could indicate that the construct is more stable compared to the other constructs.

Individual background factors that were associated with *Goals and facilitation* were length of stay with a caregiver and nights away from home. For both these variables more stability, for example, living with the caregiver for more than 10 years and not staying away from home were associated with higher levels of self-management in this sub-scale. Participants who were diagnosed at birth and on ART for more than 10 years had higher *Goals and facilitation* scores. This may mean that these participants feel more supported since they have formed relationships with healthcare providers and other HIV-positive peers and their caregivers may also be more involved in their care. Participants who felt that they were treated with respect by healthcare providers had significantly higher *Goals and facilitation* scores, indicating that healthcare workers who understand and respect adolescents may have a positive influence on their self-management. The *Goals and facilitation* SM sub-scale had a strong positive correlation (r=0.6) with the *Knowing and believing* SM sub-scale, which shows these components are related and as observed in the results, similar individual and contextual factors may influence them.

Participation involves taking action to participate in one's healthcare and in life. It could be considered to be self-management behaviours as defined in chapter 6 as managing various aspects of your disease (e.g. taking treatment as prescribed, disclosure, and attending clinic appointments). It does not, however, include treatment-taking or disclosure, but focuses on participating and communicating in the healthcare context and in the community. It is similar to Wagner's concept of the "activated" or "informed, motivated and prepared patients and families". Patients need to access medications, self-monitoring tools, and acquire self-management skills within the triad of the individual/family, the healthcare system and the community context (Epping-Jordan, Pruitt, Bengoa & Wagner, 2004:301). Within the Chronic Care Model, productive interactions between prepared proactive healthcare providers and activated patients produces good clinical outcomes (Epping-Jordan et al., 2004:300). Schulman-Green et al. (2012:136) in their self-management framework refers to processes such as utilising the healthcare system and obtaining social/community support as "activating resources". Skovdal and Daniel (2012:19) further state that active participation in decision-making improves the self-confidence of adolescents.

The items in the *Participation* sub-scale included participating in the healthcare context by attending healthcare appointments, taking part in decisions regarding health and treatment,

asking questions, communicating to healthcare providers about symptoms, missed doses and possible risk behaviours. On a personal/individual level, it means engaging in behaviours that will improve health and on a community level, adolescents should connect with friends and be involved in activities at school or within the community.

The qualitative data indicated that some adolescents attended clinic appointments on their own, especially if they were older. However, adolescents did not always attend appointments on the dates scheduled for them. Some communicated with the healthcare workers, but not consistently. It appeared as if few adolescents actively participated, or were given the opportunity to actively participate, in decisions regarding their healthcare and treatment. A few adolescents participated in activities such as sports in their community although resources for activities seemed limited. Adolescents who were in foster care appeared to know more about how to find help in the community if they needed to, such as contacting a social worker. In the fourth phase of the study, 47.1% of participants reported that they always attend clinic appointments on their own and 65.4% said they always attended on the scheduled dates. Less than half (41.6%) reported that they always took part in decisions about their health. Adolescents were more likely to always tell healthcare providers how they are feeling (49.7%) or ask questions (49.9%), than if they missed a dose of their ARVs (33.5%) or about private things (25.3%). On a personal level, only 61.6% of participants reported that they always engaged in behaviours to improve their health. With regards to the community context, less than half of the participants always had contact with friends (47.3%) or participated in activities in the community (48.5%) and 42% reported that they would always find help in the community if they needed it. The mean percentage score for *Participation* was 73.73% (SD 14.44). It can therefore be said that although participants reported generally high levels of *Believing and knowing* and *Goals and facilitation*, *Participation* levels were lower.

Participation had a Cronbach alpha of 0.715. It did not correlate stronger than the AdHIVSM-35 or other sub-scales with any variables although it had significant correlations with most of the variables, except with viral load log value, *Treatment self-efficacy*, *SLEs* and *HIV stigma* (*Negative self-image*). It may be that the construct of active participation in care and life is not captured by any of the other measures used to establish validity. The ICC for participation was 0.49, which may mean that participation varies over time. This is similar to what was reported by healthcare workers in the qualitative data, for example, some days adolescents would feel like talking and other days not.

Participation correlated the strongest with *Health-related quality of life (HRQOL)*, particularly the *Physical Activities and Health* sub-scale which may mean that participation could be related to adolescents' feeling of general well-being and particularly their energy-levels. Corbin and Strauss (1988:11) noted that variables such as mood, fatigue level, convenience

and boredom influence to what extent self-management 'work' is done. Since *HRQOL* is a distal outcome of self-management (Ryan & Sawin, 2009:217), the association provides validation for the sub-scale content. Further, adolescents who felt they were treated with respect by healthcare providers and were satisfied with services had higher levels of *Participation* that supports the notion that there is a positive interaction between an activated patient and a prepared proactive healthcare provider (Epping-Jordan et al., 2004:300). Interestingly, *Participation* was not associated with adherence or viral suppression. This may mean that an actively participating adolescent may not necessarily be an adherent one, as was discovered by Van Staa (2012:277) in her investigation in the Netherlands of the competencies of adolescents with chronic illnesses. She discovered that the self-confident and autonomous adolescent, who appeared very capable of self-management and independent participation in consultations, may also consciously decide to be non-adherent since they feel that enjoying life and participating in normal activities are more important than adhering to treatment. *Participation* had medium to strong positive correlations with all the other sub-scales of self-management, the strongest being with *Goals and facilitation* (r=0.6) which further supports the theoretical framework of this study, since SM processes are positively related to SM proximal outcomes, or in this case, *Participation*.

HIV biomedical management relates to aspects specific to HIV care, which based on the qualitative data, was generally viewed by most adolescents to be the domain of the doctor or nurse. This component was identified for the first time as being separate from the other disease-specific knowledge items in the fourth phase of the study. In both the qualitative and quantitative study phases it was identified that very few adolescents had knowledge of their viral load or what it should be. In the fourth phase of the study, 23.4% strongly agreed that they knew what their viral load is and 31.6% strongly agreed that they knew what their viral load should be. Although more than half of the participants showed interest in knowing why their viral load is high or low (59.9%), it seemed as if healthcare workers did not communicate these values to them – or if they did, they did not comprehend what it meant. It was, however, difficult to ascertain if the adolescents truly knew these values. Many of the participants who 'agreed' that they knew their viral load indicated that they 'did not know' their viral load in the first section of the questionnaire. Adolescents may therefore have reported that they knew when they did not and actual levels of this component may therefore be even lower than reported here. Another study also found that few adolescents knew their viral load or CD4 count and that discussions with the healthcare provider about CD4 and viral load were associated with higher HIV knowledge (Barnes, 2013:323). Adolescents also generally did not know the names of their ARVs since only 27.1% strongly agreed that they knew the names of their ARVs. More adolescents strongly agreed that they knew what to do if they missed a

dose of their ARVs (46.9%) compared to the other items in this sub-scale. The mean percentage score for *HIV Biomedical management* was 69.74% (SD 17.49).

The Cronbach alpha of this sub-scale was lower at 0.651. This indicated less internal consistency in the responses to items within this sub-scale, although the sub-scale had the highest average variance extracted (the items correlated well within the sub-scale). This sub-scale had the strongest negative correlation with *Symptoms* meaning that those with more knowledge of their viral load, names of their ARVs etc., reported fewer symptoms or were healthier in general. The reason is not apparent, except that symptoms to some extent relate to the construct of biomedical management of the illness. The correlation was however small (r= -0.141). *HIV biomedical management* also had a small positive correlation with the *Physical Activities and Health* sub-scale of the *HRQOL* scale (r=0.171). Participants who reported complete adherence (stating that they never skipped doses on the first Likert scale item), had significantly higher scores on this sub-scale (p=0.034), but there were no differences observed in the other adherence questions or for viral suppression. This may mean that knowledge about biomarkers minimally influences adherence behaviours or that those adolescents who were not virologically suppressed may have more knowledge of these biomarkers due to undergoing intensified adherence counselling as reported by Chandwani et al. (2012:242). One participant in the qualitative study phase commented that he sometimes does not use a condom since he knew his viral load was low. There were, however, no difference in mean *HIV biomedical management* scores between participants who used condoms consistently and those who did not.

The ICC for *HIV biomedical management* was the lowest at 0.427. It may be that overall adolescents are less involved in this aspect of care and therefore were uncertain when answering questions. It may also be that the first administration of the questionnaire triggered them to enquire about some of these aspects of care since the mean score of this sub-scale was slightly, though significantly, higher for the re-test (Mean=11.65) compared to the first administration (Mean=10.83). The *HIV biomedical management* score was significantly lower for participants who completed the questionnaire with a fieldworker that may mean that the fieldworkers may have questioned the adolescents' understanding of the items, leading them to select more 'honest' responses to these questions. However, it may also be that fieldworkers assisted adolescents who were cognitively challenged and may not have comprehended these values. *HIV biomedical management* was the only sub-scale that had a significant difference in mean scores between participants who enjoyed/liked coming to the clinic/hospital and those who did not. Those who enjoyed coming to the clinic had higher *HIV biomedical management* scores, which may mean that adolescents with more 'specialised' disease-specific knowledge enjoy coming to the clinic more, perhaps because they have more understanding or are more interested in knowing about their disease.

Coping and self-regulation as defined in chapter 6 includes being in control, recognising illness and the need for further consultation, making independent decisions regarding your health and collaborating with others. Self-regulation includes decision-making, planning, goal-setting, self-evaluation and coping. In this sub-scale *Coping and self-regulation* was specifically directed at coping with HIV stigma and self-regulating more complex aspects of healthcare and living such as disclosure, dealing with negative emotions, for example, to continue to take treatment when one does not want to and planning how to take treatment when not at home. The abovementioned issues have been identified as known challenges of living with HIV (Swendeman et al., 2010:6; Mburu, et al., 2014:14). "Living with a chronic illness", for example, coping, readjusting and integrating, is included in the components of the self-management framework identified by Schulman-Green et al. (2012:136).

From the qualitative data, it was apparent that healthcare workers questioned the ability of adolescents to demonstrate self-regulation skills, although some adolescents did demonstrate skills such as planning and problem solving that were mostly related to taking treatment and disclosing their HIV status. It was apparent that coping with HIV stigma was the greatest challenge for adolescents and that most used passive emotion-focused strategies such as ignoring comments or avoiding certain situations in order to cope. Some adolescents used substances, especially when their diagnosis were first disclosed to them. For the questions relating to coping with stigma and disclosure-related stress, 48.4% and 57.5% indicated that they would not cope if they were rejected by friends following disclosure or if someone says hurtful things about people living with HIV. Some adolescents (13.6%) indicated that they always, or most of the time, coped by eating unhealthy food or using substances. In terms of dealing with medication/adherence related stressors, the qualitative data revealed that most adolescents accepted that they have to take treatment and took it even if they did not feel like it. However, there were adolescents who expressed that they did not take their treatment when they felt down or depressed, deliberately discontinued their treatment for a period of time or skipped doses due to goal incongruence. The quantitative data indicated that 32.4% of participants still relied on people to remind them to take their treatment, 19.1% reported other things interfered with their plans to take their treatment and 31.1% did not take their ARVs if they did not want to. Only 48.3% strongly agreed that they planned how to take their treatment when they were not at home. Further, 14.3% of adolescents had stopped their treatment in the past of whom most indicated that they became tired of taking their treatment or that it was too hard for them to take treatment every day. More than half (56.1%) of adolescents agreed or strongly agreed that they made decisions about to whom to disclose their HIV status to. In the qualitative interviews is was clear that decisions about whether to disclose or to whom to disclose was based on the perceived trust they had in the person. The mean percentage score for *Coping and self-regulation* was the lowest of all the sub-scales

(68.60%, SD 17.09). This supports the qualitative data that revealed that coping with HIV stigma, disclosure and taking ownership of taking treatment, are aspects of self-management that are challenging for adolescents.

This sub-scale had the lowest internal consistency (0.547). Based on the qualitative and quantitative data, the sub-scale includes items that are considered more challenging for adolescents. Their individual skills for *Coping and self-regulation* may be at different levels and dependent on the specific task. Adolescents may therefore have good self-management in one aspect, for example, planning to take their treatment when not at home, but have difficulty coping with HIV stigma or vice versa. Although this sub-scale correlates with *Barriers to adherence*, *Resilience, HRQOL* and *SLEs*, correlations were not stronger compared to the AdHIVSM-35 and the other sub-scales. As with sub-scale 3, it may be that the construct of coping and self-regulation of disease-specific aspects of healthcare and life are not being captured by any of the other measures used to validate the instrument. Although *Coping and self-regulation* did not correlate with overall *HIV stigma*, a significant negative correlation was identified between this sub-scale and the HIV stigma sub-scale *Disclosure concerns* ($r= -0.152$, $p<0.01$). Further, the *Coping and self-regulation* sub-scale positively correlated with the *Friends* sub-scale of the HRQOL scale ($r= 0.207$, $p<0.001$). This may mean that quality friendships have a positive influence on adolescents coping and self-regulation skills. Older adolescents (16-18) had a slightly higher mean score compared to younger adolescents (13-15), although the mean difference was not significant. The mean of behaviourally-infected adolescents were significantly higher than perinatally-infected adolescents. Since behaviourally-infected adolescents are likely to be older, it may be that they have better coping skills due to their age. It may also be that they are less 'protected' and therefore have to learn to cope more quickly than perinatally-infected adolescents. Participants who completed isiXhosa questionnaires had significant lower mean *Coping and self-regulation* scores. Similarly, isiXhosa home language-speaking adolescents had a lower mean score, although differences between groups was not significant. The discrepancy may be because many isiXhosa home language-speaking adolescents either completed English or Afrikaans questionnaires since that was the language they were schooled in or were more comfortable with. The relationship between home language and this component of self-management may therefore need to be explored further. The ICC for coping and self-regulation was high at 0.727, which may mean that it is a more stable component of self-management and that adolescents' coping and self-regulation skills are unlikely to change unless these skills are taught to them. The WHO (2010:17) Integrated Management of Adolescent and Adult Illness (IMAI) which focused on adolescents living with HIV, notes that skills and healthy behaviours should be taught/established during early adolescence before unhealthy or risk behaviours commence.

The total AdHIVSM-35 did not differentiate between participants of different genders or home languages. It was expected that older adolescents would demonstrate higher self-management, but the results showed no differences between the young adolescents (13-15) and the older adolescents (16-18). A reason for this could be that the young adolescents tend to answer questions without truly evaluating what the question is asking and that older adolescents perhaps have more self-knowledge or insight to respond accurately. This was demonstrated during the cognitive questioning performed in the focus groups in the third study phase described in chapter 6 and also reported by Lippman et al. (2014:35). Another explanation could be the individual differences between adolescents. Adolescence is a phase where individual differences among peers of the same age are noticeable, which may be further influenced by the variable effect of HIV on development (Newman & Newman, 2012:337; WHO, 2010:14). The trend noticed of an apparent drop in self-management around the age of 16 may be an accidental finding or it may indicate that middle adolescence is a period where adolescents need more support with self-management. They may be transitioning from being dependent on their caregivers to becoming more independent and they may also start exploring and become more involved in risky behaviours.

Family background variables such as with whom the adolescents resided and the level of education of the caregiver were not associated with total AdHIVSM-35, which was surprising. However, adolescents who reported staying with a family member such as an aunt, grandmother, sister or brother, were less likely to be virologically suppressed compared to staying with biological or adoptive parents ($p=0.035$) and more likely to report binge-drinking ($p=0.037$). This may mean that these adolescents are likely to be less supervised, but do not necessarily experience less support as there were also no difference in the *Family and Free Time* scores on the HRQOL measure between the groups. Evidence related to the influence of family socioeconomic status (SES) on self-management are mixed. Grey et al. (2006:280) report that lower SES is associated with poorer self-management, whereas Müller et al. (2010:129) reported in their study that family socioeconomic factors were not associated with treatment outcomes in South-African children. In this study socioeconomic factors were not specifically investigated.

The only illness/treatment variables that affected AdHIVSM-35 scores were whether participants knew by which route they were infected and the frequency of taking treatment. Knowledge of the route of infection may be an indication of how often the adolescent have engaged in conversations with healthcare workers or caregivers about their illness or their readiness to accept their diagnosis. It corresponds with the qualitative data indicating that adolescents and caregivers generally do not speak about HIV at home and that the route of infection may be a particularly sensitive topic, especially in the context of perinatal HIV infection. Frequency of doses and a complex treatment regimen has been associated with

treatment non-adherence and with lower self-management, since it is more difficult to integrate treatment in to the adolescent's routine (Chandwani et al., 2012:242; Cox et al., 2014:126). Twice daily doses were also identified in the qualitative phase of this study as difficult for adolescents to manage, since they usually forgot the morning dose.

Variables related to the healthcare context such as being treated with respect, being satisfied and enjoying coming to the clinic or hospital were associated with higher self-management scores. This was also identified in the qualitative data and means that healthcare setting interventions focused on educating healthcare workers to be more mindful of the needs of adolescents may positively affect their self-management (Modi et al., 2012:479; Mburu et al., 2014:9; Schulman-Green et al., 2012:140; Maskew et al., 2016:4; Kisesa & Dick, 2016:S4).

One aspect that was not adequately addressed by the developed AdHIVSM-35 measure was risk behaviours. Only one question addressed risk behaviours and was not included for factor analysis due to it only applying to about a third of the participants. However, of those who answered the question (n=120), only 60.8% reported consistent condom use which is similar to what was reported in the sexual behaviour section of the questionnaire. The question about using substances such as drugs or alcohol to cope was eventually deleted from the AdHIVSM measure due to it lowering the internal consistency of one of the sub-scales. This could have been due to it being a reverse-scored item as discussed in chapter 7. Risk behaviours were however a concern with 19.6% of participants reporting binge-drinking, 44.2% reporting inconsistent condom use and 23% reporting multiple partners. Further development and testing of the developed AdHIVSM-35 measure should focus on including items that could address risk behaviours. This measure or component should likely be kept separate since it may not apply to all adolescents.

8.2.2 Research question 2: What would be the structure, components and items of an instrument that incorporates the context and realities of adolescent HIV self-management?

There were six sub-themes identified under the main theme of self-management in the qualitative data. These sub-themes were considered to be components of self-management and included *Knowing and understanding*; *Believing and valuing*; *Self-regulation*; *Coping*; *Communication and disclosure*; and *Social facilitation*. Through a process of comparing the qualitative findings with the literature, 55 items were written that encompassed the components of self-management. One additional sub-category, namely *Goals* were added under the main component of *Self-regulation* and *Coping* was grouped under *Self-regulation*. The concept of 'resource utilisation' was added to the description of the social facilitation component. These 55 items were then reviewed by adolescents and caregivers to ascertain

their validity, contextual and developmental appropriateness. An additional 10 items were added to the list and some items refined, although the main components remained the same. A group of experts then reviewed the 65 items. Based on content validity and clarity indexes, 21 items were deleted and some refined resulting in a final list of 44 items. The components changed slightly, grouping *Communication* under *Social facilitation* and adding a separate component for *Self-management behaviours,* since some items were more suited as a behaviour than a process. During the pilot test, none of the self-management items were changed.

The self-management items were then administered to a sample of 385 adolescents. Item 44 that related to condom use was removed since it applied to only a third of the sample. Confirmatory factor analysis (CFA) did not indicate a good model-fit (RMSEA=0.065; CFI=0.8; GFI=0.79) with the theorised components and therefore exploratory factor analysis (EFA) was performed. Five main components were extracted through EFA that were similar to the theoretical framework of the study and explained 34.5% of the total scale variance. Eight items, that did not meaningfully load on any factor or reduced the reliability of the identified sub-scales, were removed. The five components were: *Believing and knowing* (8 items); *Goals and facilitation* (8 items); *Participation* (10 items); *HIV biomedical management* (4 items); and *Coping and self-regulation* (5 items). The developed AdHIVSM-35 measure had acceptable internal consistency and test-retest reliability. CFA on the instrument structure identified through the EFA indicated a good model fit (RMSEA=0.052; CFI=0.9; GFI=0.86). The composite reliability of the final sub-scales were above 0.7, discriminant validity of the sub-scales were established and all the items had significant factor loadings. However, the average variance (AVE) of the subscales were less than desirable, although it may still be acceptable due to AVE being a strict measure of convergent validity. The sub-scales had significant correlations with other variables in the hypothesised directions supporting their validity, although most correlations indicated a small to medium effect. Validity coefficients should be significant at the 0.05 level and have a value of at least 0.3 (Foxcroft & Roodt, 2009:53). The AdHIVSM-35 had correlations of above 0.3 with the *Resilience* and *HRQOL* measures. The *Believing and knowing* subscale had correlations above 0.3 with *Barriers to adherence* and *Resilience*; *Goals and facilitation* correlated above 0.3 with *HRQOL* and *Participation* had a correlation above 0.3 with *HRQOL*. The sub-scales *HIV biomedical management* and *Coping and self-regulation* had significant correlations with other scales, but not at the 0.3 level. The AdHIVSM-35 differentiated between adherent and non-adherent participants as well as virologically suppressed and unsuppressed participants. However, ROC analysis indicated that AdHIVSM-35 scores did not accurately predict viral suppression.

Through this study a measure for adolescent HIV self-management (AdHIVSM-35) was developed that consisted of five sub-scales. Evidence from the study indicate that it is a

reliable and valid measure that can be used to measure adolescent HIV self-management in a South African context. However, the structure of the measure should be further tested and confirmed through CFA on another sample of the target group. Further research is needed to investigate how measurement error can be reduced that may improve the convergent validity of the sub-scales.

8.3 REFLECTION ON THE INSTRUMENT DESIGN PROCESS

Reflecting on the instrument design process, I realised that I found it challenging in many ways. At the onset of the study I underestimated the time and depth of engagement necessary to design a meaningful instrument. The process changed me on a personal and professional level. Personally, due to my prolonged interaction with adolescents living with HIV, their caregivers and healthcare workers during the study, my understanding of self-management and the components thereof, continued to change. The question that occupied my thoughts the most was what makes adolescents who manage well different from the ones who do not. I contemplated the differences amongst adolescents I observed – their physical appearance, how they engaged with me and how they completed the questionnaires. Some adolescents appeared to develop completely normally despite being infected perinatally, while others appeared young for their age. Certain adolescents struggled to write their own name and could not read questions, while others completed the questionnaires completely independently. I also became intensely aware of the social and economic difficulties of adolescents and their families within the communities and the immense disparity, which made me very empathetic towards adolescents and caregivers. Yet, most participants were doing well despite their circumstances. Although the study has revealed more about how adolescents who live with HIV self-manage in a South African context, more research is needed to explore the differences I observed.

Professionally I learned new skills in qualitative and quantitative research methods. Although I have been trained and involved in qualitative and quantitative research studies, Interpretive Phenomenology and Factor Analysis were methods completely new to me. With regards to the instrument design process, I was not aware of the many rigorous steps involved. In my previous experience with research instruments, I have noticed that nurse researchers do not always consider the contextual and cultural appropriateness of instruments and rarely adequately take the reliability and validity of an instrument into account.

Due to being closely involved with the data collection process in the fourth phase of the study and being present when participants completed questionnaires, I realised that the process of instrument development may have limitations. Even after following a set of rigorous processes to ensure that items are clear and relevant, a self-completion questionnaire may still not yield

'accurate' and 'objective' results. Each individual interprets the questions based on their own reality, previous experiences and how they feel at a particular moment in time. This makes measuring an abstract concept such as adolescent HIV self-management very difficult, especially with a group such as adolescents. Further, the adolescent's response to a particular question may differ depending on their context or situation. For example, one participant wrote on her questionnaire 'at school' when she responded to certain items on the *HIV stigma* scale that could mean that she delimited her response to the school context. When asked about contradictory responses on the *Mood and Feelings* sub-scale of HRQOL, one participant responded that he was in a good mood very often, but that he was also very often sad at school. This may mean that the adolescent's mood and feelings are affected by the environment or context they find themselves in.

What stood out the most for me during the final phase of the study was the issue of literacy or language ability. In a multicultural society such as South Africa, it is challenging to use a consistent way of administering a set of items. Although the largest proportion of the sample was isiXhosa-speaking, many could not read isiXhosa. Written isiXhosa is also very different from the spoken colloquial isiXhosa. Some isiXhosa home language speakers went to an Afrikaans school and preferred Afrikaans questionnaires or chose English, since the sentences were shorter compared to the isiXhosa questionnaire. During the phase four feedback meeting, most of the fieldworkers felt that reading and explaining questions to participants worked better overall, since it was the best way to ensure the participants understood the questions correctly. The pitfall with that was that the fieldworkers tended to explain items using their own interpretation when a participant did not understand, even if they were told to keep to the wording of a particular item. During questionnaire administration, some participants wanted questions to be read to them, while others did not want help, even when offered. This may indicate that the personality of the adolescent also affects which method of questionnaire administration they prefer.

Reflecting on the steps used to design the instrument, I feel that I could have done another round of cognitive interviews on the 44-item translated AdHIVSM before including the other sections of the questionnaire and undertaking the pilot study. Although none of the participants in the pilot study identified issues with the questions, in-depth questioning on their understanding in their preferred language may have led to the revision of some items. The next step in further developing the instrument should therefore be to perform individual cognitive questioning of the translated AdHIVSM with at least five Afrikaans, five English and five isiXhosa-speaking participants. In order to establish instrument validity, many other measures were included which made the questionnaire very long and participants may have become fatigued causing them to select responses without reflecting on the questions. It may be better to choose only one or two other measures with which to establish validity, to shorten

the questionnaire. The other measures chosen should also undergo cultural adaptation and validation before they are used. Another issue to consider is the participants' reading level. The reason why a self-completion pen-and-paper method was chosen was because it may be easy to eventually implement it in the clinical setting without healthcare workers having to interview the adolescent. However, it was evident that in the study context, home language literacy was problematic, especially for isiXhosa-speaking participants and participants with learning difficulties. Computer-assisted self-interview (ACASI) software devices may therefore have to be used with such participants. Using software programmes may also be more beneficial for calculating AdHIVSM-35 and sub-scale scores and for identifying areas for which adolescents need assistance. Another option could be to use a cellular phone-based software application that could be installed on the adolescent's phone. Resources for such devices are however limited and it may not be practical to implement.

One aspect that was not adequately addressed in the developed AdHIVSM-35 is risk behaviours. The question on condom use only applied to a third of adolescents and it was therefore removed from further analysis. However, the quantitative data indicated that the adolescents engaged in several risk behaviours. Further research is therefore needed to develop a component of self-management that targets risk behaviours.

Nevertheless, the developed instrument is the first of its kind to include all the SM process constructs identified in the IFSMT and to illustrate the relationship between the constructs. The relationship between the constructs are congruent with the IFSMT supporting the use of the theory. It is an instrument that has been inductively developed through the use of key informant input to ensure its cultural, contextual and developmental appropriateness and is the only known self-management instrument developed in an African context.

8.4 LIMITATIONS OF THE STUDY

The limitations for each phase of the study were discussed in chapter 3. Here the limitations that influence the generalisability of the study findings and other practical limitations are discussed.

The participants who particiapted in the development of the instrument were from an urban setting. Most were from a lower socio-economic class and lived in townships (informal housing estates). The largest proportion of participants were perinatally-infected with HIV and isiXhosa-speaking. Although no differences could be found in the overall self-management scores based on the route of infection or language, inclusion of other population groups and behaviourally-infected adolescents is necessary for the further development of the instrument.

Due to the large volumes of data and the focus on instrument development, the essences of the participants' lived experiences as it relates to adolescent HIV self-management in the first study phase may lack extensive layering. Further, explication and understanding of the Heidegerrian concepts such as being in the world, encounters with entities and care structure could have been emphasized.

For the quantitative phase, participants were recruited consequtively, meaning that only those participants who attended the clinic or hospital had a chance to be included in the study. Although all the adolescents who met the study inclusion criteria and agreed to participate were included, there may have been bias in selecting participants who have better self-management in general. Random selection of participants is, however, very challenging, since participants who do not attend the clinic will have to be traced via telephone or home visits, which is problematic due to the incorrect contact details in patient folders and the difficulty of locating homes. For example, in an effort to locate the caregiver of one of the adolescents, it was discovered that he had moved to stay with a different caregiver of whom the contact details were not available.

Data on the 'gold standard' of viral load measurement had to be obtained from patient folders. In many cases the viral load was not current, since it is only performed annually. Evaluating missed clinic appointments as an observable indicator of good self-management was also problematic due to caregivers or 'buddies' sometimes collecting treatment on behalf of the adolescent and the long intervals (2-3 months) between clinical appointments. To adequately assess the relationship between self-management and the participant's viral load, the viral load will have to be measured at the same time as the completion of the questionnaire. This does, however, have implications for the budget of future studies and it may change the risk-benefit assessment, since the participants will have to undergo an additional test that is not part of routine care. Further, viral load may not be a good criterion with which to measure self-management, due to it primarily reflecting medication self-management.

The instrument was completed either individually, with some assistance or by reading the questions to the participants. This was neccesary due to the variablity amongst participants in terms of reading literacy and the participants' preference. It would have been better if the instrument was administered in a consistent manner. Although no differences were identified in the overall self-management scores and the way the instrument was administered, it would be better in future studies to use an approach that accommodates participants with poor reading literacy, for example, using ACASI software.

8.5 KEY FINDINGS

The study set out to identify how adolescent HIV Self-Management (AdHIVSM) is realised in a South African context and to identify the structure and components of an instrument that will measure AdHIVSM. Items were inductively developed through interviews with adolescents, caregivers and healthcare workers who were considered to have in-depth knowledge of adolescent HIV self-management. Interpretive phenomenology was used to situate the experiences of participants in their social and cultural context and relate it to the components of the theoretical framework of the study and the literature. Further, adolescents and caregivers had an opportunity to evaluate whether these items resonated with their experiences in a workshop using focus groups and cognitive questioning. Following this, a group of experts evaluated the content validity and clarity of each item that assisted in reducing the initial 65 items to 44 highly relevant items. The developed AdHIVSM measure consisting of 44 items and 10 other questionnaire sections were translated into Afrikaans and isiXhosa and piloted with adolescents of the target group. Finally, the questionnaire was administered to 385 adolescents from 11 different healthcare facilities in the Cape Metropole in order to establish validity and reliability.

Confirmatory factor analysis (CFA) on the theoretical measurement structure did not indicate a good model-fit and therefore exploratory factor analysis (EFA) was performed. Five components of adolescent HIV self-management was identified though EFA: *Believing and knowing; Goals and facilitation*; *Participation*; *HIV biomedical management*; and *Coping and self-regulation*. These components were meaningful and could be related to the theoretical framework of the study and the qualitative data. The final AdHIVSM consisted of 35 items as nine items were removed through the process of EFA and sub-scale reliability testing. The developed AdHIVSM-35 had acceptable internal consistency reliability and stability. The sub-scales had acceptable internal consistency reliability, but some of the sub-scales had undesirable stability and questionable convergent validity. CFA on the structure developed through EFA indicated a good model-fit that supported its structural validity. However, the components need to be confirmed through further research.

The study provides evidence that participants who had higher self-management had better HIV-related (adherence and viral suppression) and general health outcomes (health-related quality of life), which supports the criterion- and convergent validity of the identified components. These components could therefore be used as a guideline to develop AdHIVSM education programmes in a South African context. Improving the self-management of adolescents may lead to better disease-specific and general health outcomes.

Contextual issues that need to be addressed in order to improve adolescents' self-management and health outcomes include equipping caregivers with skills to support

adolescents with self-management, focusing on the process of knowledge transfer of disease-specific information, screening and appropriately referring adolescents with behavioural/emotional difficulties or learning disabilities, tailoring healthcare services to the needs of adolescents, improving resilience resources and reducing HIV stigma.

8.6 RECOMMENDATIONS

Based on the study findings, the research process and observations made while collecting data, several recommendations are made.

8.6.1 Self-management education for healthcare workers, adolescents and caregivers

Self-management education should be implemented in healthcare settings for adolescents and caregivers. Self-management education for adolescents should be focused on teaching self-management skills such as coping with stigma, setting goals, planning and problem solving. In addition, caregivers need to be equipped with knowledge and skills in order to support adolescents with self-management. This includes HIV-specific knowledge, knowledge related to the adolescent phase and skills such as effective communication and discipline. Family members need to be made aware of their central role in influencing the beliefs and knowledge of adolescents. The involvement of family members in adherence programmes has shown promise to improve adherence to ART (Lyon, Trexler, Akpan-Townsend, Pao, Selden et al., 2004:299). However, self-management is a broader concept and therefore SM education should include aspects of social and emotional management (Lorig & Holman, 2003:4).

Healthcare workers need to be trained on how to provide self-management education and on the difference between self-management education and general health education. Further, self-management education should be focused on the needs of adolescents. Self-management education can follow the five A's approach (assess, advise, agree, assist and arrange) recommended by WHO (2010:73). Healthcare workers also need to be made aware of how to work with and approach adolescents and that their behaviour may influence the adolescent's self-management.

8.6.2 Increased focus on the process of disease-specific knowledge acquisition

Just as disclosure should not be treated as a once-off event, knowledge of one's illness should also be treated as a process of acquiring knowledge. An increased focus on making healthcare workers and caregivers aware that disclosure is only the beginning of a process of

knowledge acquisition is necessary. Healthcare workers and caregivers should use every opportunity to engage with adolescents and enquire about their knowledge of the disease, even if the adolescent seems uninterested at the time and not only when an adherence problem is evident. Knowledge will also be easier to transfer if the adolescent is ready and receptive. It is, therefore, important to ask the adolescent what are the issues or questions they have and focus on those in a stepwise manner.

It is important for healthcare workers to keep contact with caregivers, even if the adolescent attends the clinic alone. During the data collection process, it was observed that although many caregivers did not attend appointments with their adolescent, they had many questions and concerns. Better communication between healthcare workers and caregivers is therefore essential in order to optimally support adolescents with self-management. Using electronic platforms may be useful to enhance communication and can serve as support structures for caregivers as well as adolescents. However, in the study context, some adolescents and caregivers may not have access to this since they do not have mobile phones or have only one mobile phone in the family. A study on the usefulness of a virtual support group using MXit for adolescents 12-25 in the same study setting found that adolescents had a desire to interact with peers through social media, but that the cost of using social media and anonymity were issues (Henwood, Patten, Barnett, Hwang, Metcalf et al., 2016:898), which may be the same for caregivers.

8.6.3 Screening for neurocognitive disabilities and emotional/behavioural difficulties with appropriate referral/interventions

More than a third of adolescents (36.2%) were not in the correct grade for their age and some were considered to be ‘slow learners’. However, many were not in a special school or did not receive any intervention or treatment in order to assist them. Caregivers in the first study phase mentioned that they did not have the money and resources to assist their children if they needed help in school. Almost a quarter (24.6%) of participants had an emotional and behavioural difficulties score classified as borderline or abnormal. It is, therefore, recommended that every HIV-positive child and adolescent should be evaluated by a trained professional for neurocognitive and learning disabilities as well as emotional/behavioural difficulties. Screening should be done as early as possible to prevent further delay in development. Affected adolescents should be appropriately referred. Neurocognitive and psychological assessment has also been advised by Lee and Hazra (2015:1) and Lowenthal et al. (2014:24). Further, HIV-positive adolescents who are hospitalised or have to stay home for prolonged periods due to illness, for example multidrug-resistant TB, should have access to home schooling or additional support in order to ensure that they do not fall behind in school.

8.6.4 Youth-friendly approach to care

The extent to which services are focused on the needs of adolescents may have an important influence on their self-management abilities, especially their participation in care. The literature shows that healthcare workers should be prepared and proactive (Epping-Jordan et al., 2004:300). This will require that healthcare workers are trained on how to communicate with and deliver care to adolescents.

Healthcare settings such as clinics and hospitals need to be made more accessible for young people so that they are not deterred through stigma. Not all healthcare facilities have the capacity for separate adolescent services, but changes in the organisation of care could improve the accessibility of care for adolescents. For example, if HIV stigma is a concern in the setting, adolescents could be seen in the afternoon after school or they could be seen in a venue not designated exclusively for HIV-positive people. This may also minimise interruptions with their school schedule. Key aspects to focus on is reducing the waiting time of adolescents and treating them with respect. Continuity of healthcare workers is important to build a relationship with adolescents. Further, having food available and organising activities for adolescents are important motivating factors for them to attend clinic appointments. Government funding should be made available to ensure that services are more adolescent-friendly. These recommendations are supported by other studies (Tanner, et al., 2014:199; Maskew et al., 2016:3; Kisesa & Dick, 2016:S4).

8.6.5 Considerations for research with adolescents who live with HIV

More research on adolescents who live with HIV is necessary. However, there are several barriers to research amongst adolescents that should be unpacked amongst researchers and academics with an interest in this topic. This includes the difficulty of obtaining access to this group, parental consent for research and the challenges with language, literacy and cognitive ability. To increase research in this population, clear guidelines with regards to parental informed consent and adolescent assent is needed. Guidelines should differentiate between studies with a low risk-benefit ratio and studies that may have a higher level of risk. Currently all research with children under the age of 18 in South Africa requires parental/guardian consent. However, this is contradictory to other legislation stating that a child can consent on his/her own if they fully understand the risks/benefits, social and other implications involved (Republic of South Africa, 2005:59). Therefore, Research Ethics Committees currently hold the power to grant a waiver of parental consent if duly motivated by the researcher. Researchers would, however, benefit from clear guidelines with regards to research with adolescents to guide them when developing proposals. Furthermore, funding is needed to

train fieldworkers, develop multi-pronged interventions and culturally-appropriate measurement tools that target adolescents.

8.6.6 Use of the IFSMT

The research has shown that the concepts of the IFSMT is applicable in a South African context with an adolescent HIV-infected population group. This increases the parsimony of the theory. The use of this theory is therefore recommended to further the understanding of the components of self-management in this context.

8.6.7 Use of the developed AdolHIVSM-35

The AdHIVSM-35 is a comprehensive instrument that meaningfully incorporates the components of adolescent HIV self-management. It can therefore be used in practice as a tool to identify adolescents at risk for poor self-management. The questions/items can be used to guide discussions or educational sessions around adolescent HIV self-management. The findings show that completion of the questions in itself, without any further discussion, may also lead to improved self-management. However, healthcare workers should assess whether an adolescent has been fully disclosed to about their HIV status before administering the questionnaire to them.

8.6.8 Future research

The following areas for future research are proposed:

- Further testing the developed AdHIVSM-35 and sub-scales through conducting another round of cognitive interviews and performing Confirmatory Factor Analysis on a large, separate sample.
- Exploring how to measure self-management of risk behaviours as an added component to the AdHIVSM-35.
- Implementing a self-management intervention that targets the components of SM identified in this study and measuring whether it will increase AdHIVSM.
- Exploring how caregivers and healthcare workers can be involved and trained to support adolescents with self-management.

8.7 DISSEMINATION

The research will be disseminated through feedback that will be given to the Department of Health, the City of Cape Town and the individual clinics involved. The research findings will be presented at various platforms and conferences both nationally and internationally. Further, articles will be published in peer-reviewed journals.

8.8 CONCLUSION

The study aim was to conceptualise adolescent HIV self-management in a South-African context and develop an instrument to measure AdHIVSM that is contextually and developmentally appropriate using a mixed-method approach. The components of AdHIVSM identified through this study include: *Believing and knowing*; *Goals and facilitation*; *Participation*; *HIV biomedical management*; and *Coping and self-regulation*. These components need to be further explored through research before the AdHIVSM-35 can be confirmed to be a valid and reliable measure for AdHIVSM in a South African context. The study provides evidence that higher self-management, as measured with the developed AdHIVSM-35, is associated with better adherence, health-related quality of life and virological suppression. Interventions focused on increasing AdHIVSM through emphasis of these components may therefore lead to better health outcomes for adolescents who live with HIV.

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APPENDICES

APPENDIX 1: ETHICAL APPROVAL DOCUMENTS FROM STELLENBOSCH UNIVERSITY

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Approval Notice
New Application

20-May-2015
Crowley, Talitha T

Ethics Reference #: S15/03/054
Title: **The conceptualisation and measurement of adolescent HIV self-management in a South African context.**

Dear Mrs. Talitha Crowley,

The **New Application** received on **20-Mar-2015**, was reviewed by Health Research Ethics Committee 1 via Committee Review procedures on **06-May-2015** and has been approved.
Please note the following information about your approved research protocol:

Protocol Approval Period: **06-May-2015 -06-May-2016**

Present Committee Members:
Weber, Franklin CFS
Unger, Marianne M
Barsdorf, Nicola N
Botha, Paul JP
Decloedt, Eric EH
Rohland, Elvira EL
Hoek, Kim KGP
Werely, Cedric CJ
Hendricks, Melany ML
Ferris, William WF
Welzel, Tyson T
Abulfathi, Ahmed AA
Mukinda, Fidele FK

Ethics Letter

24-Nov-2015

Ethics Reference #: S15/03/054
Clinical Trial Reference #:
Title: The conceptualisation and measurement of adolescent HIV self-management in a South African context.

Dear Mrs. Talitha Crowley,

The HREC approved your application for an amendment to the protocol dated 16 September 2015.

If you have any queries or need further assistance, please contact the HREC Office 0219389657.

Sincerely,

REC Coordinator
Franklin Weber
Health Research Ethics Committee 1

Ethics Letter

23-Mar-2016

Ethics Reference #: S15/03/054
Title: The conceptualisation and measurement of adolescent HIV self-management in a South African context.

Dear Mrs. Talitha Crowley,

The HREC approved the following progress report by expedited review process:

Progress Report dated 15 March 2016

The approval of this project is extended for a further year

Approval date: 23 March 2016

Expiry date: 22 March 2017

Ethics Letter

25-Apr-2017
Crowley, Talitha T

Ethics Reference #: S15/03/054
Title: The conceptualisation and measurement of adolescent HIV self-management in a South African context.

Dear Mrs. Talitha Crowley

The HREC approved your Progress Report dated 03 February 2017.

Approval date: 23 March 2017

Expiry date: 22 March 2018

APPENDIX 2: PERMISSION OBTAINED FROM WESTERN CAPE DEPARTMENT OF HEALTH AND CITY OF CAPE TOWN

Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 6857; fax: +27 21 483 9895
5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
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REFERENCE: **WC_2015RP53_21**
ENQUIRIES: Ms Charlene Roderick

Stellenbosch University
Private Bag X1
Matieland
7602

For attention: **Talitha Crowley**

Re: THE CONCEPTUALISATION AND MEASUREMENT OF ADOLESCENT HIV SELF-MANAGEMENT IN A SOUTH AFRICAN CONTEXT.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.
Please contact the following people to assist you with any further enquiries in accessing the following sites:

CITY OF CAPE TOWN
ISIXEKO SASEKAPA
STAD KAAPSTAD

CITY HEALTH

Dr Hélène Visser
Manager: Specialised Health

T: 021 400 3981 **F:** 021 421 4894 **M:** 083 298 8718
E: Helene.Visser@capetown.gov.za

2016-07-12

Re: Research Request: The conceptualisation and measurement of adolescent HIV self-management in a South African context (6508) (ID No: 10540)

Dear Dr Crowley,

Your research has been approved to explore the nature and healthcare needs of adolescents living with HIV around self-management to develop and psychometrically evaluate a measurement instrument in a South African context.

APPENDIX 3: PARTICIPANT INFORMATION LEAFLET AND DECLARATION OF CONSENT BY PARTICIPANT AND INVESTIGATOR

PARTICIPATING HEALTHCARE PROVIDER / ACADEMIC INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: Conceptualising and measuring adolescent HIV self-management in a South African context

REFERENCE NUMBER: S15/03/054

PRINCIPAL INVESTIGATOR: Talitha Crowley

ADDRESS: Faculty of Medicine and Health Sciences: Division Nursing
Francie van Zijl Drive
Tygerberg 7500
South Africa

CONTACT NUMBER: 076 945 3993

Dear Colleague

You are invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Your participation is **entirely voluntary** and you are free to decline this invitation to participate. If you decline, this will not affect you negatively in any way whatsoever. If you do agree to take part, you are free to withdraw from the study at any point.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- This study aims to identify the components of adolescent HIV self-management (how adolescents living with HIV take care of themselves) in order to develop an instrument (questionnaire) that will measure whether adolescents living with HIV can take care of themselves with the assistance of their caregiver (parent or legal guardian) and the assistance of their healthcare providers.
- The study will be conducted at health facilities where adolescents living with HIV receive care.
- We will recruit adolescents living with HIV, caregivers, healthcare providers and academics to provide their views on the important parts of adolescent HIV self-management.
- We will then ask adolescents, caregivers, health workers and academics to develop an instrument to measure adolescent HIV self-management through focus group workshops.
- The developed instrument (questionnaire) will then be tested with a group of adolescents and their caregivers.
- In the final phase of the study, the instrument (questionnaire) will be validated by comparing it to other measures such as adolescent adherence, viral load and health-related quality of life. A large group of adolescents from different health facilities will complete the questionnaires in this phase.

- Identifying and measuring the components of adolescent HIV self-management may help us to better support adolescents living with HIV.
- Adolescents will receive no additional treatment or intervention and will continue with their standard care while participating in the study.

Why have you been invited to participate?

- You have been invited to participate because you are a healthcare provider or academic with experience in caring for adolescents living with HIV or because you are knowledgeable about adolescent health issues.
- We think that you could make a valuable contribution to identifying the important aspects of adolescent HIV self-management (how adolescents living with HIV take care of themselves).
- You can assist us to develop an instrument to measure adolescent HIV self-management.

What will your responsibilities be?

You may be asked to participate in one or both of the following:

- You may be asked to participate in a face-to-face interview of about **one hour**. In the interview you will be asked to share your experiences of caring for adolescents living with HIV and your thoughts about the important things adolescents should do in order to take care of themselves.
- You may also be asked to provide feedback with other healthcare providers or academics on a list of items developed for an adolescent HIV self-management measure.

Will you benefit from taking part in this research?

- Participation in this study will be of no direct personal benefit to you. You may however use the information from this study to help you identify aspects of self-management in which adolescents need support with.

Are there any risks involved in your taking part in this research?

- There are no anticipated risks for you in participating in this study. The study may however take at least two to four hours of your time, which may be an inconvenience to you.

If you do not agree to take part, what alternatives do you have?

- You do not have to participate in the study. Should you wish to participate but the times proposed by the researcher do not fit your schedule, you are welcome to inform the researcher so that other arrangements can be made for you.

Who will have access to your medical records or information?

- All information will be treated confidentially and be protected. Only the researcher and study supervisors will have access to your information. Interviews will be written up using false names. Your identity will therefore remain anonymous.
- All audio recordings and transcripts will be kept in electronic password-protected folders.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

- We do not anticipate that you will suffer any injury or harm as a result of taking part in the study.

Will you be paid to take part in this study and are there any costs involved?

- There will be no costs involved for you if you do take part.

Is there anything else that you should know or do?

- You may contact Talitha Crowley on cell phone number 076 945 3993 if you have any queries or encounter any problems.
- You may contact the Health Research Ethics Committee on telephone number 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

Declaration by participating healthcare provider / academic

By signing below, I ……..……. agree to take part in a research study entitled ***'Conceptualising and measuring adolescent HIV self-management in a South African context'.***

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I understand that I may choose to leave the study at any time and will not be penalised or prejudiced in any way as a consequence.
- I consent to the audio recording of any interviews or focus group I may be involved in.

Signed at (*place*) .....…..…….. on (*date*) ……...……...

....
Signature of participant **Signature of witness**

Declaration by investigator

I ……..……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

Signed at (*place*) .....…..…….. on (*date*) ……...……...

....
Signature of investigator **Signature of witness**

PARTICIPATING CAREGIVER (PARENT OR LEGAL GUARDIAN) INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: Conceptualising and measuring adolescent HIV self-management in a South African context

REFERENCE NUMBER: S15/03/054

PRINCIPAL INVESTIGATOR: Talitha Crowley

ADDRESS: Faculty of Medicine and Health Sciences: Division Nursing
Francie van Zijl Drive
Tygerberg 7500
South Africa

CONTACT NUMBER: 076 945 3993

Dear Caregiver (Parent or Legal Guardian)

You are invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Your participation is **entirely voluntary** and you are free to decline this invitation to participate. If you decline, this will not affect you negatively in any way whatsoever. If you do agree to take part, you are free to withdraw from the study at any point.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- This study aims to identify the components of adolescent HIV self-management (how adolescents living with HIV take care of themselves) in order to develop an instrument (questionnaire) that will measure whether adolescents living with HIV can take care of themselves with the assistance of their caregiver (parent or legal guardian) and the assistance of their healthcare providers.
- The study will be conducted at health facilities where adolescents living with HIV receive care.
- We will recruit adolescents living with HIV, caregivers, healthcare providers and academics to provide their views on the important parts of adolescent HIV self-management.
- We will then ask adolescents, caregivers, health workers and academics to develop an instrument to measure adolescent HIV self-management through focus group workshops.
- The developed instrument (questionnaire) will then be tested with a group of adolescents and their caregivers.
- In the final phase of the study, the instrument (questionnaire) will be validated by comparing it to other measures such as adolescent adherence, viral load and health-related quality of life. A large group of adolescents from different health facilities will complete the questionnaires in this phase.
- Identifying and measuring the components of adolescent HIV self-management may help us to better support adolescents living with HIV.
- Adolescents will receive no additional treatment or intervention and will continue with their standard care while participating in the study.

Why have you been invited to participate?

- You have been invited to participate because you are a caregiver (parent or legal guardian) of an adolescent living with HIV and have at least one year of experience in caring for an adolescent living with HIV.
- We think that you could make a valuable contribution to identifying the important aspects of adolescent HIV self-management (how adolescents living with HIV take care of themselves).
- You can assist us to develop an instrument to measure adolescent HIV self-management.

What will your responsibilities be?

You may be asked to participate in one or both of the following:

- You may be asked to participate in a face-to-face interview of about **one hour**. In the interview you will be asked to share your experiences of caring for adolescents living with HIV and your thoughts about the important things adolescents should do in order to take care of themselves.
- You may also be asked to participate with other caregivers in a workshop of about **three to four hours** to assist us in identifying questions we can ask adolescents to see if they can take care of themselves.

Will you benefit from taking part in this research?

- Participation in this study will be of no direct personal benefit to you. You may however use the information from this study to help you identify aspects of self-management in which your child need support with.

Are there any risks involved in your taking part in this research?

- There are no anticipated risks for you in participating in this study. The study may however take at least one to four hours of your time, which may be an inconvenience to you.

If you do not agree to take part, what alternatives do you have?

- You do not have to participate in the study. Should you wish to participate but the times proposed by the researcher do not fit your schedule, you are welcome to inform the researcher so that other arrangements can be made for you. The care of your child will not be affected in any way if you choose not to participate in the study.

Who will have access to your medical records or information?

- All information will be treated confidentially and be protected. Only the researcher and study supervisors will have access to your information. No names will be written on questionnaires. Interviews will be written up using pseudonyms (false names). Your identity will therefore remain anonymous. All participants in the focus group workshop will be asked to keep information shared in the focus group confidential.
- All audio recordings and transcripts will be kept in electronic password-protected folders.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

- We do not anticipate that you will suffer any injury or harm as a result of taking part in the study. Should you however become distressed during the interview or focus group workshop you will be referred for counselling if you so wish.

Will you be paid to take part in this study and are there any costs involved?

- You will not be paid to take part in the study but your transport costs will be covered for each study visit if you incurred such costs. **This will be in the form of an R80 voucher for participating in an interview or focus group.** Refreshments will be provided during the interview and focus group workshop. There will be no costs involved for you if you do take part.

Is there anything else that you should know or do?

- You may contact Talitha Crowley on cell phone number 076 945 3993 if you have any queries or encounter any problems.
- You may contact the Health Research Ethics Committee on telephone number 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records if you so wish.

Declaration by participating caregiver

By signing below, I ……..…….. agree to take part in a research study entitled ***'Conceptualising and measuring adolescent HIV self-management in a South African context'.***

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I understand that I may choose to leave the study at any time and will not be penalised or prejudiced in any way as a consequence.
- I consent to the audio recording of any interviews or focus group I may be involved in.

Signed at (*place*) .....…..…….. on (*date*) ……...……...

....
Signature of participant **Signature of witness**

Declaration by investigator

I ……..……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

Signed at (*place*) .....…..…….. on (*date*) ……...……...

....
Signature of investigator **Signature of witness**

NON-PARTICIPATING LEGAL GUARDIAN INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: Conceptualising and measuring adolescent HIV self-management in a South African context

REFERENCE NUMBER: S15/03/054

PRINCIPAL INVESTIGATOR: Talitha Crowley

ADDRESS: Faculty of Medicine and Health Sciences: Division Nursing
Francie van Zijl Drive
Tygerberg 7500
South Africa

CONTACT NUMBER: 076 945 3993

Dear Non-participating Legal Guardian

Your child is invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you and your child could be involved. The participation of your child is **entirely voluntary** and you are free to decline this invitation to your child to participate. If you decline, this will not affect you or your child negatively in any way whatsoever. If you do agree that your child may take part, you are free to withdraw your child from the study at any point.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- This study aims to identify the components of adolescent HIV self-management (how adolescents living with HIV take care of themselves) in order to develop an instrument (questionnaire) that will measure whether adolescents living with HIV can take care of themselves with the assistance of their caregiver and their healthcare providers.
- The study will be conducted at health facilities where adolescents living with HIV receive care.
- We will recruit adolescents living with HIV, caregivers, healthcare providers and academics to provide their views on the important parts of adolescent HIV self-management.
- We will then ask adolescents, caregivers, health workers and academics to develop an instrument to measure adolescent HIV self-management through focus group workshops.
- The developed instrument (questionnaire) will then be tested with a small group of adolescents and their caregivers.
- In the final phase of the study the instrument (questionnaire) will be validated by comparing it to other measures such as adolescent adherence, viral load and health-related quality of life. A large group of adolescents from different health facilities will complete the questionnaires in this phase.
- Identifying and measuring the components of adolescent HIV self-management may help us to better support adolescents living with HIV.
- Adolescents will receive no additional treatment or intervention and will continue with their standard care while participating in the study.

Why has your child been invited to participate?

- Your child is invited to participate because he/she is between the ages of 13 and 18 and is living with HIV.
- We think that your child could make a valuable contribution to identifying the important aspects of adolescent HIV self-management (how adolescents living with HIV take care of themselves).
- Your child can assist us to develop an instrument to measure adolescent HIV self-management.

What will your child's responsibilities be?

- **(1)** Your child may be asked to participate in a face-to-face interview of about **one hour**. In the interview your child will be asked to share his/her experiences of living with HIV and his/her thoughts about the important things adolescents should do in order to take care of themselves.

OR

- **(2)** Your child may be asked to participate with other adolescents in a group discussion of about **one hour** about how adolescents should take care of themselves.

OR

- **(3)** Your child may be asked to complete a questionnaire of about **45 minutes** during one of his/her regular clinic visits.

If you child has participated in (1) or (2) above,

- Your child may also be asked to participate with other adolescents in a focus group discussion of about **three to four hours** to assist us to identify questions we can ask adolescents to see if they can take care of themselves.

Will you or your child benefit from taking part in this research?

- Participation in this study will be of no direct personal benefit to you or your child.
- You may however use the information from this study to help you identify aspects of self-management in which your child need support with.

Are there any risks involved for you or your child in taking part in this research?

- There are no anticipated risks for your child in participating in this study. The study may however take at least 45 minutes to four hours of your child's time, which may be an inconvenience to you.
- If the researcher identifies any form of child abuse during the interviews or group discussion, it will be reported to the authorities.

If you do not agree that your child may take part, what alternatives do you have?

- You do not have to permit your child to participate in the study. Should you want your child to participate and the times proposed by the researcher do not fit your schedule, you are welcome to inform the researcher so that other arrangements can be made for your child. The care of your child will not be affected in any way if you choose not to give permission for him/her to participate in the study.

Who will have access to your child's medical records or information?

- All information will be treated confidentially and be protected. Only the researcher and study supervisors will have access to your information. No names will be written on questionnaires. Interviews will be written up using pseudonyms (false names). Your child's identity will therefore remain anonymous. All participants in the focus groups will be asked to keep information shared in the focus group confidential.
- If the researcher discovers any form of child abuse during the interviews or group discussion, the researcher is responsible by law to report it to the authorities.
- All audio recordings and transcripts will be kept in electronic password-protected folders.

What will happen in the unlikely event of some form of injury occurring as a direct result of your child taking part in this research study?

- We do not anticipate that your child will suffer any injury or harm as a result of taking part in the study. If your child becomes distressed during the interview or focus group he/she will be referred to the counsellor on the premises of the health facility.

Will you or your child be paid to take part in this study and are there any costs involved?

- Your child will not be paid to take part in the study but the transport costs of your child will be covered for each study visit if you incurred any such costs. The costs are calculated as follows:
  - **Your child will get an R80 voucher for participating in an interview or focus group outside regular clinic visit days.**
  - **Your child will get an R30 voucher for completing a questionnaire on a regular clinic visit.**
- Refreshments will be provided during the interviews and focus groups. There will be no costs involved for your child, if he/she does take part.

Is there anything else that you should know or do?

- You may contact Talitha Crowley on cell phone number 076 945 3993 if you have any queries or encounter any problems.
- You may contact the Health Research Ethics Committee on telephone number 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records if you so wish.

Declaration by legal guardian

By signing below, I ……..…….. agree that my child may take part in a research study entitled ***'Conceptualising and measuring adolescent HIV self-management in a South African context'.***

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to give permission for my child to take part.
- I accept that my child may choose to leave the study at any time and may not be penalised or prejudiced in any way as a consequence.
- I consent to the audio recording of any interviews or focus group my child may be involved in.

Signed at (*place*) .....…..…….. on (*date*) ……...……...

....

Signature of guardian **Signature of witness**

Declaration by investigator

I ……..……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

Signed at (*place*) .....….....…….. on (*date*) ……...……...

....

Signature of investigator **Signature of witness**

ADOLESCENT PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM

TITLE OF THE RESEARCH PROJECT: *Understanding how adolescents with HIV take care of themselves with the assistance of their caregivers (parents or legal guardians) and health workers.*

RESEARCHER'S NAME: Talitha Crowley

ADDRESS: **Faculty of Medicine and Health Sciences: Division Nursing**
Francie van Zijl Drive, Tygerberg 7500, South Africa

CONTACT NUMBER: 076 945 3993

What is research?

Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find out more about disease or illness. Research also helps us to find better ways of helping or treating adolescents who are sick.

What is this research project all about?
This study is about understanding how adolescents living with HIV take care of themselves with the assistance of their caregivers (parents or legal guardians) and healthcare workers.

Why have you been invited to take part in this research project?
You have been invited to take part because you are living with HIV. We would like to know more about how you take care of yourself and who supports you.

Who is doing the research?
My name is Talitha Crowley. I am a nurse and I work for Stellenbosch University. I am doing this study because I am interested to know how adolescents with HIV take care of themselves.

What you will do in this study?
You will be expected to do **one or two** of the following:

- ✓ Spend about **one hour** talking to me about how you take care of yourself.
- ✓ Be part of a group discussion of about **one hour** about how adolescents with HIV take care of themselves.
- ✓ Be part of a working group of about **three to four hours** where you and other adolescents will work on a list of things adolescents should do in order to take care of themselves.
- ✓ Complete a questionnaire of **about 45 minutes** about how you take care of yourself and some other questions about yourself.

Can anything bad happen to you?
You may feel uncomfortable when you are asked certain questions and you can tell me if you do not feel comfortable to speak. You do not have to answer questions that you do not want to answer. I will not tell your caregivers (parents or legal guardians) or the health workers about the things we have talked about, but if you tell me that bad things were done to you by anyone, I have to report these things.

Will anything good happen?
Your story may help us to understand how adolescents take care of themselves so that we can help other adolescents to take care of themselves.

- You will be given a **voucher of R80** to cover your travel costs if you participate in an interview or focus group outside the normal days you come to the clinic.
- If you are chosen to complete a questionnaire, you will be given an **R30 voucher** if you complete the questionnaire.

Will anyone know I am in the study?
The healthcare workers of this clinic will know that you are taking part in this study. I also need to ask your caregiver (parent or legal guardian) if he/she agrees that you can take part in this study. I will not tell the healthcare workers or your caregiver (parent or legal guardian) about the things you have talked about. Our discussion will be just between you and me, and nobody else will know that it was you who said certain things.

Who can you talk to about the study?
You can talk about the study with your health worker (nurse or doctor) and you can contact me (Talitha Crowley) on my cell phone number 076 945 3993 if you have any questions about the study.

What if you do not want to take part?
You do not have to be a part of the study if you do not want to. The health workers and your caregiver (parent/s or legal guardian/s) will not be mad at you if you do not feel like taking part.

Even if your caregiver (parent/s or legal guardian/s) have said you may take part, you do not have to take part if you do not want to. If you agree to take part and later feel that you do not want to take part anymore, you can just tell me how you feel and stop participating in the study without any problem.

Do you understand this research study and are you willing to take part in it?

YES NO

Can the researcher make an audio recording of the interview or focus group? / Can the research access your folder to obtain information about the tablets you are taking, your blood results and how often you attend the clinic? *(select the applicable option)*

YES NO

Has the researcher answered all your questions?

YES NO

Do you understand that you may withdraw from the study at any time?

YES NO

Name and surname of adolescent: _____ Signature:_____
Age/DOB:_____ ***you must be between 13 and 18 years old to participate**
Date:_____

Name and surname of parent/guardian:_____
Contact number:_____

ADOLESCENT (18 YEARS) INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: Conceptualising and measuring adolescent HIV self-management in a South African context

REFERENCE NUMBER: S15/03/054

PRINCIPAL INVESTIGATOR: Talitha Crowley

ADDRESS: Faculty of Medicine and Health Sciences: Division Nursing
Francie van Zijl Drive
Tygerberg 7500
South Africa

CONTACT NUMBER: 076 945 3993

Dear Adolescent

You are invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Your participation is **entirely voluntary** and you are free to decline this invitation to participate. If you decline, this will not affect you negatively in any way whatsoever. If you do agree to take part, you are free to withdraw from the study at any point.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- This study aims to identify the components of adolescent HIV self-management (how adolescents living with HIV take care of themselves) in order to develop an instrument (questionnaire) that will measure whether adolescents living with HIV can take care of themselves with the assistance of their caregiver and their healthcare providers.

Why have you been invited to participate?

- You have been invited to participate because you are between the ages of 13 and 18 and are living with HIV.
- We think that you could make a valuable contribution to identifying the important aspects of adolescent HIV self-management (how adolescents living with HIV take care of themselves).
- Your can assist us to develop an instrument to measure adolescent HIV self-management.

What will your responsibilities be?

<u>You will be expected to do one or two of the following:</u>

- Spend about one hour talking to me about how you take care of yourself.
- Be part of a group discussion of about one hour about how adolescents with HIV take care of themselves.
- Be part of a working group of about three to four hours where you and other adolescents will work on a list of things adolescents should do in order to take care of themselves.

- Complete a questionnaire of about 45 minutes about how you take care of yourself and some other questions about yourself.

Will you benefit from taking part in this research?

- Participation in this study will be of no direct personal benefit to you.
- You may however use the information from this study to help you identify aspects of self-management in which you need support with.

Are there any risks involved for you in taking part in this research?

- There are no anticipated risks for you in participating in this study. The study may however take at least 45 minutes to four hours of your time, which may be an inconvenience to you.

If you do not agree that you may take part, what alternatives do you have?

- You do not have to participate in the study. Should you want to participate and the times proposed by the researcher do not fit your schedule, you are welcome to inform the researcher so that other arrangements can be made for you. Your care will not be affected in any way if you choose not to participate in the study.

Who will have access to your medical records or information?

- All information will be treated confidentially and be protected. Only the researcher and study supervisors will have access to your information. No names will be written on questionnaires.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

- We do not anticipate that you will suffer any injury or harm as a result of taking part in the study. If you become distressed during the interview or completion of the questionnaire, you will be referred to the counsellor on the premises of the health facility.

Will you be paid to take part in this study and are there any costs involved?

- You will not be paid to take part in the study, but you will get a R80 voucher for participating in an interview or focus group and a R30 voucher for completing a questionnaire on a regular clinic visit.
- There will be no costs involved, if you take part.

Is there anything else that you should know or do?

- You may contact Talitha Crowley on cell phone number 076 945 3993 if you have any queries or encounter any problems.
- You may contact the Health Research Ethics Committee on telephone number 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records if you so wish.

Declaration by adolescent (18 years)

By signing below, I ……..…… agree that I will take part in a research study entitled ***'Conceptualising and measuring adolescent HIV self-management in a South African context'.***

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I accept that I may choose to leave the study at any time and may not be penalised or prejudiced in any way as a consequence.
- I consent to the researcher audio recording the interview or focus group / obtaining information about my medication, my blood results and how often I come to the clinic from my patient folder.

Signed at (*place*) .....…..…….. on (*date*) ……...……...

....
Signature of adolescent **Signature of witness**

Declaration by investigator

I ……..……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

Signed at (*place*) .....…..…….. on (*date*) ……...……...

....
Signature of investigator **Signature of witness**

SCRIPT FOR TELEPHONIC CONSENT: NON-PARTICIPATING LEGAL GUARDIAN

Hallo, my name is Talitha Crowley (replace with fieldworker name where necessary) and I am conducting a research study on how adolescents living with HIV can take care of themselves.

The study has been approved by the Health Research Ethics committee at Stellenbosch University and the clinic/hospital where your child is receiving care.

Your child has indicated that they would like to participate in the study. However, I need your permission for your child can participate in the study. The participation of your child is entirely voluntary and he/she do not have to participate. Your child can also withdraw at any point without his/her care being affected.

Your child will be asked to (participate in an interview of about 1 hour / participate in a focus group of about 1 hour / complete a questionnaire of about 45 minutes) about how he/she manage him/herself and some other questions related to his/her background and health. Your child will also be asked to give permission for the researcher to audio record the interview / focus group or access his/her health record to obtain information about the medication he/she is using, blood results and how often he/she attends the clinic. All their other care at the clinic/hospital will remain as usual. All information will be kept confidential.

Your child will get an R80 voucher for participating in an interview or focus group and a R30 voucher for completing a questionnaire.

You may contact me on cell phone number 076 945 3993 if you have any queries. I will send a copy of the information about the study home with your child if you so wish.

Do you understand the purpose of the study and what is required? YES/NO

Do you have any questions? YES/NO

Do you agree that your child can participate? YES/NO

APPENDIX 4: PHASE 1 INTERVIEW GUIDES

Healthcare Worker

You are aware from the consent form that I am interested in

Tell me about the work you do here in managing adolescents living with HIV.

Context of clinic

Tasks part of job

Tell me the HIV+ adolescents that come to your clinic

Age race class background

Health

Level of maturity

Social connectivity

Mental health

Comparison to other adolescents in the community

Tell me what you think the most important things adolescents need to know and do in order to self-manage their chronic condition (HIV) / to look after themselves.

Medical management

Emotional management

Social / role management - social connections, family connectivity

What do you think will make it easier for them to self-manage their HIV?

Individual – personality, attitude, problem solving skills, sense of self-worth

Home family

Community

School

Friends/peer relationships

Health symptoms mental health

Understanding of their disease

Stigma

Capacity to see their own future and sense of control over it (goals/dreams)

What do you think will make it difficult for them to self-manage their HIV?

As above

Can you describe any ways in which you think adolescents can be supported effectively to manage their own chronic disease?

Support Peers Family School Clubs

Counselling support, Behavioural interventions

Adolescent

You are aware from the consent form that I am interested in

Tell me about a bit about yourself

How old are you, where do you stay, who do you live with

Where do you go to school, what grade

Tell me about coming to this clinic

How long have you been coming, how often do you have to come, do you come alone, who sees you, what do they do / talk to you about, do you like coming to the clinic

Tell me what you think the most important things you need to know and do in order to self-manage your chronic condition (HIV) / to look after yourself.

Medical (health/treatment related) management

Emotional management

Social / role management - social connections, family connectivity

What do you think will make it easier for you to self-manage your HIV?

Individual – personality, attitude, problem solving skills, sense of self-worth

Home family

Community

School

Friends/peer relationships

Health symptoms mental health

Understanding of their disease

Stigma

Capacity to see their own future and sense of control over it (goals/dreams)

What do you think will make it difficult for you to self-manage your HIV?

As above

Can you describe any ways in which you think adolescents can be supported effectively to manage their own chronic disease?

Support Peers Family School Clubs

Counselling support

Behavioural interventions

Caregiver

You are aware from the consent form that I am interested in

Tell me about yourself

Where do you live, work, how many children, how old is your (adolescent), how long have you been taking care of them,

Tell me about coming to the clinic

How often do you come, do you come with them to the clinic, who sees you at the clinic, what do they talk about / do, do you like coming to the clinic

Tell me what you think the most important things adolescents need to know and do in order to self-manage their chronic condition (HIV) / to look after themselves.

Medical (health / treatment related) management

Emotional management

Social / role management - social connections, family connectivity

What do you think will make it easier for them to self-manage their HIV?

Individual – personality, attitude, problem solving skills, sense of self-worth

Home family

Community

School

Friends/peer relationships

Health symptoms mental health

Understanding of their disease

Stigma

Capacity to see their own future and sense of control over it (goals/dreams)

What do you think will make it difficult for them to self-manage their HIV?

As above

Can you describe any ways in which you think adolescents can be supported effectively to manage their own chronic disease?

Support Peers Family School Clubs

Counselling support

Behavioural interventions

APPENDIX 5: CONFIDENTIALITY AGREEMENT WITH DATA TRANSCRIBER

CONFIDENTIALITY AGREEMENT

I, the undersigned _Leigh Story

1. herewith undertake that all information disclosed or submitted, either orally, in writing or in other tangible or intangible form by Talitha Crowley to me, or made available to me, or details of Talitha Crowley's business or interest of which I may become aware of in respect of transcriptions being done by myself for Talitha Crowley, to keep confidential and not to divulge to anyone for which Talitha Crowley did not give written consent;

2. guarantee that I will apply the information, detail or knowledge in **clause 1** only for the purpose of the intended research;

3. indemnify Talitha Crowley against any claims that may be instituted against Talitha Crowley, amounts that may be claimed or losses that Talitha Crowley may suffer in consequence of a violation by me of any provision included in this agreement.

SIGNED at Cape Town on __ _____

APPENDIX 6: EXCERPT OF TRANSCRIBED INTERVIEW

[Male adolescent 2, 14 years]

IV Okay, so when you come to the clinic what usually happens here at the clinic?

IE Just stay and wait until they do the check-up and stuff. The doctor takes you and asks you are you well and stuff, is there any pain. Then after that they take you, they take the folder and they send you to that room that we're here in, and they take you there, and you wait for your medicine now there, by the medicine cupboard. Then they call your name and then you take your tablets, and then you go.

IV Okay, and how long does that take?

IE Sometimes it takes very long. Like sometimes it takes very quick, we don't know what happened.

IV Okay [laughs]. Do you like coming to the clinic?

IE Yes, I like coming.

IV Okay, why do you like coming?

IE Because, I like coming because I take my tablets and stuff and then that tablets make me alive and stuff, and that I don't die.

IV Okay, so you know you have to take your treatment?

IE Yes, every day.

IV Okay, and who helps you to take your treatment?

IE My mother, and if I forget, then she says I must take my tablets, and my father also. They always remind me to take my tablets.

IV Okay. So what do you think do you need to do every day to manage yourself and to live with HIV?

IE Just eat your tablets and then you'll be fine.

IV You'll be fine, okay. Is there anything else that you think you need to do?

IE Eat healthy, and do a lot of activities and stuff to keep your body like fit and stuff also.

IV Okay, and when it comes to school, is there anything at school that you think you need to do?

IE You need to work hard, and don't fail, and pass every year, and go on to the next grade and develop more education and stuff.

IV Okay, and with your friends?

IE No, my friends, it's just with friends you don't talk about serious stuff and life and so. You just play, play, play.

IV So you enjoy each other, being together, doing things together.

IE Yes, you don't talk about any stuff that is serious around the world.

IV Okay [chuckles], and in your family, you said your relatives?

IE Ja, I just go there to like see how they are, and is there sickness or something like that, and I go to my cousins also.

IV If you think now about every day, your life, what makes it easy for you to manage yourself, to take your tablets and to live with HIV? What makes it easy?

IE You don't like think about I have HIV and stuff, and then you don't, like when you play, you just don't feel that thing, that pain that you have HIV, maybe something that can be done. You don't feel alone and that people don't want to be next to you if you have HIV. You just play and then you don't talk about it.

IV You don't? So it’s easy for you to just play and not to talk about it?

IE Yes.

IV So your friends, do they know that you are HIV positive?

IE No,

IV They don't? And you will also not tell them?

IE No.

IV Okay, so you like to play and not think about it too much?

IE Yes.

IV And just live your life like normal?

IE Yes.

IV And who taught you that?

IE It’s just something of my own.

APPENDIX 7: PERMISSION FOR USE OF INSTRUMENTS

HIV-ASES:

Tue 12/07/2016 15:13
Johnson, Mallory <Mallory.Johnson@ucsf.edu>
RE: HIV-ASES
To Crowley, T, Mev <tcrowley@sun.ac.za>

I think those modifications make sense given the context and changes in HIV treatment. Best of luck in your work.
Mallory

HIV stigma:

Tue 05/07/2016 09:14
Lise-Lott Rydström <lise-lott.rydstrom@ki.se>
HSSC-8
To Crowley, T, Mev <tcrowley@sun.ac.za>
Message HSSC-8 2016-06-04.pdf

Dear Talitha Crowley

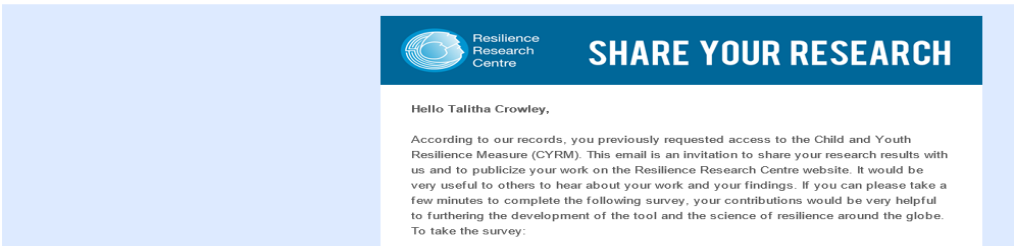
Thank you for your interest of the HSSC-8. Dr Wiklander is on vacation so she asked me to answer you regarding the question if you could use the HSSC-8. On the research group`s behalf I can say that you can feel free to use the scale provided that you refer to the article:

Wiklander M, Rydström LL, Ygge BM, Navér L, Wettergren L, Eriksson LE.Psychometric properties of a short version of the **HIV** stigma scale, adapted for children with **HIV** infection. Health Qual Life Outcomes. 2013 Nov 14;11:195. doi: 10.1186/1477-7525-11-195.

Furthermore our research group is interested to see the results from your study using this survey. If you are interested I insert three other articles that our group of researchers has published regarding children and young adults living with a perinatal HIV infection.

CRYM:

Wed 29/06/2016 16:59
Resilience Research Centre <rrc@dal.ca>
Share your Research Results: CYRM!
To Crowley, T, Mev <tcrowley@sun.ac.za>
If there are problems with how this message is displayed, click here to view it in a web browser.



KIDSCREEN-27:

Thu 16/02/2017 14:40
Office of Quality of Life Measures <QOL@uke.de>
AW: KIDSCREEN-27
To Crowley, T, Mev <tcrowley@sun.ac.za>
Cc Ravens-Sieberer, Ulrike
You replied to this message on 16/02/2017 15:22.
Action Items + Get more ap

Dear Talitha Crowley,

Thank you for your quick response. I am really glad that you are so hardworking on the translation. Thank you very much for your effort, already.
In the regular procedure, we check the finalized translation before it is used for the pre-test. But as you have already started, I would suggest that you continue with your pre-test while we are checking your backward translation here. Please give me some time to check the files you sent to me. I will send them back to you with my remarks (if there should be any). At the same time, please let me know, if you will do any changes because of your pre-test.
If the pre-test is working well and we do not have any remarks (or in case we have some, they will be changed or explained) we will approve your language version and would be really happy to be able to provide language versions for South Africa.

I wish you all the best for the pre-tests and your further studies.

With best regards,
Toni Maria Klein
KIDSCREEN Group Europe

APPENDIX 8: TRANSLATION OF QUESTIONNAIRE

TAALSENTRUM
LANGUAGE CENTRE
IZIKO LEELWIMI

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

01 August 2017

Ms Talitha Crowley
Faculty of Medicine and Health Sciences
Division of Nursing Science
PO Box 241
Cape Town
8000

Dear Ms Crowley

Questionnaire and KIDSCREEN-27

The Stellenbosch University Language Centre hereby confirms that we delivered the following services:

1. Editing of your English *Adolescent Selfcare Questionnaire (which consisted of 12 sections: Background information; Your symptoms; Your treatment; Your clinic or hospital; Taking care of yourself; Your life events; Your quality of life (KIDSCREEN-27); Your strengths and difficulties; Your use of alcohol and drugs; Your sexual behaviour; How you experience stigma; and Your resilience)* ensuring that the text is on grade 6 reading level.
2. Adolescent Selfcare Questionnaire (except KIDSCREEN-27) – translated into Afrikaans, and back-translated, authenticated and reconciled keeping the reading level in mind.
3. Adolescent Selfcare Questionnaire (except KIDSCREEN-27) – translated into isiXhosa, and back-translated, authenticated and reconciled keeping the reading level in mind.
4. KIDSCREEN-27 – translation by two independent translators into Afrikaans, reconciliation of the two Afrikaans translations, back-translation and further adaptation of the Afrikaans translation, where necessary.
5. KIDSCREEN-27 – translation by two independent translators into isiXhosa, reconciliation of the two isiXhosa translations, back-translation and further adaptation of the isiXhosa translation, where necessary.

Please contact me should you have any queries.

Regards

MvdWaal

Marguerite van der Waal
Head: Language Service
Stellenbosch University Language Centre
Tel: 021 808 3096
Fax: 021 808 2863
E-mail: mvdwaal@sun.ac.za

APPENDIX 9: PHASE 4 QUESTIONNAIRE

Research number	☐☐☐

HOW YOU TAKE CARE OF YOURSELF

This study is about understanding how young people living with HIV take care of themselves with the assistance of their parents or caregivers, and healthcare workers.

You have been invited to take part because you are living with HIV. We would like to know more about how you take care of yourself and who supports you. Remember that you may choose to take part or not, which means that you don't HAVE to do it. The information you give will be used for research – and it will remain anonymous (your name won't be used) and confidential (private). If you do volunteer to complete this questionnaire, you will get a R30 voucher.

You may choose to:

1. Ask the research assistant to read the questions to you and complete it on your behalf.
2. Ask the research assistant to read the questions to you and answer questions yourself.
3. Read and answer the questions yourself.

   If you choose to answer the questions yourself, please mark your answers directly onto this booklet. If you need help, please ask one of the research assistants.

FOR OFFICE USE												
Site:												
Participant code:												
Consent given by:												
Data collector name and surname:												
Date:	2	0	1	Y	M	M	D	D				
Information given by:		Participant only			Participant with help							
		Fieldworker & participant										

Division of Nursing
University of Stellenbosch
tcrowley@sun.ac.za

1 BACKGROUND INFORMATION

Please tell us a bit more about yourself. If there is more than one option at a question, choose the best one, and only mark one answer.

QUESTIONS ABOUT YOU

1 Date of birth ☐Y ☐Y ☐Y ☐Y ☐M ☐M ☐D ☐D

2 Home language ☐ IsiXhosa ☐ Afrikaans ☐ English Other _____

3 Are you currently in school? ☐ Yes ☐ No

4 What is the highest grade that you have completed?

☐ Grade 5 ☐ Grade 6 ☐ Grade 7 ☐ Grade 8 ☐ Grade 9
☐ Grade 10 ☐ Grade 11 ☐ Grade 12

5 I see myself as: ☐ Male ☐ Female ☐ I choose not to say ☐ Transgender

6 My ID document says that I am: ☐ Male ☐ Female ☐ I choose not to say

QUESTIONS ABOUT YOUR FAMILY

7 Whom do you consider to be your family? (For example, it could be one or two biological parents, grandparents, aunt and/or uncle, siblings, friends on the street, a foster family or an adoptive family)

_____

_____

8 With whom do you stay? That will be your primary caregiver or the person who looks after you.

☐ Biological mother ☐ Family member (aunt, grandmother, sister, brother, etc.)
☐ Biological father ☐ Adoptive parents
☐ Biological father and mother ☐ Other _____

9 How long have you lived with the person who looks after you?

☐ Less than one year ☐ 1-5 years ☐ 6-10 years ☐ More than 10 years

10 What is the level of education of the person who looks after you?

☐ No formal schooling ☐ Primary school ☐ High school
☐ College or university ☐ Not sure/don't know

11 How many people live in the same house as you? (Include yourself when you count) ____

12 How many times have you moved house in the past 5 years? (Please tick the correct number)

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐ More than 5.

13 In the past week, how many nights have you stayed away from home?

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7

14 Is your biological mother still alive? ☐ Yes ☐ No ☐ Not sure

15 Is your biological father still alive? ☐ Yes ☐ No ☐ Not sure

16 Are you still in touch with your biological mother or father?

☐ Yes, with my mother and my father ☐ Yes, only with my mother ☐ Yes, only with my father
☐ No

QUESTIONS ABOUT YOUR HEALTH

17 When were you diagnosed with HIV?

☐ At birth ☐ Before the age of 6 ☐ Between 6 and 12
☐ After the age of 12 ☐ I don't know

18 At what age did you find out that you are HIV positive?

☐ Between the ages of 6 and 10 ☐ After the age of 12
☐ Between the ages of 10 and 12

19 What is your most recent CD4 cell count? _____ (Write it down if you know it)
☐ Don't know/not sure

20 What is your most recent viral load? _____ (Write it down if you know it)
☐ Undetectable
☐ Don't know/not sure

21 Do you have any other health conditions or illnesses at the moment?

☐ Yes ☐ No ☐ I don't know

Please mark the illnesses that you have, or write them down if they are not on this list:

☐ High blood pressure ☐ Malaria ☐ Hepatitis ☐ TB
☐ Depression ☐ Diabetes ☐ ADHD

Other _____

22 How did you become infected with HIV? Please circle 'Yes' or 'No' for each line.

At birth/from my mother (mother-to-child transmission)	Yes	No
By having sex	Yes	No
Forced sex or abuse	Yes	No
Shared needles or recreational drug equipment	Yes	No
Blood transfusion or other medical procedure	Yes	No
I don't know/I'm not sure	Yes	No

2 YOUR SYMPTOMS

1 Below we ask you about symptoms you might have had during the PAST MONTH
Please tick the box that describes how much each symptom bothered you.

During the past month I felt like this:		I don't have this symptom	It doesn't bother me	It bothers me a little	It bothers me a lot
a	Tiredness or loss of energy.				
b	Dizziness or lightheadedness.				
c	Forgetfulness.				
d	Nausea, vomiting or stomach pain.				

During the past month I felt like this:		I don't have this symptom	It doesn't bother me	It bothers me a little	It bothers me a lot
e	Feeling sad, down or depressed.				
f	Nervousness or anxiousness.				
g	Difficulty falling asleep or staying asleep.				
h	Skin problems (like rashes, dryness or itchiness).				
i	Coughing or trouble catching your breath.				
j	Headaches.				
k	Not feeling hungry or changes in the taste of food.				
l	Muscle aches or joint pains.				

2 **Do you have any other symptoms?**

☐ No

☐ Yes (please write them down): _____

3 YOUR TREATMENT

1 **Which of these three choices describes you best? Choose one.**

☐ I have never taken ARVs **(please skip all the questions in this section and go to section 4).**

☐ I am taking ARVs at the moment **(please go on to question 2).**

☐ I started taking ARVs but I've stopped taking it **(please skip questions 2-8 and continue from question 9 of this section).**

2 **How long have you been taking HIV medication (ARVs)? Choose one.**

☐ Less than one year ☐ 1-5 years ☐ 6-10 years

☐ More than 10 years ☐ Don't know/Not sure

HOW ARE YOU TAKING YOUR ARVs?

3 **How many tablets do you take every day? Choose one.**

☐ 1 ☐ 2 ☐ 3 ☐ More than 3 ☐ Don't know/not sure

4 **How often do you have to take your tablets? Choose one.**

☐ Once a day (for example, evening only)

☐ Two times a day (for example, morning and evening)

☐ More than two times a day (for example, morning, lunch and evening)

☐ Don't know/Not sure

5 **When was the last time you missed taking any of your ARVs? (for example, you skipped taking your tablets completely)**

☐ Within the past week ☐ 1-3 months ago

☐ 1-2 weeks ago ☐ More than 3 months ago

☐ 2-4 weeks ago ☐ Never skip medication/not applicable

6 **In general, over the PAST MONTH, how often did you miss taking your ARVs?**

☐ I hardly ever take any of my ARVs ☐ I miss my ARVs a little bit of the time

☐ I miss most of my ARVs ☐ I never miss any of my ARVs

☐ I miss about half of my ARVs

7 **How many times did you miss taking your ARVs over the LAST WEEK?**

0	1	2	3	4	5	6	7

8 **People miss taking their medication for various reasons. If you think back, please choose all the reasons you missed taking your ARVs over the PAST MONTH, and show how often that happened.**

	Over the past month:	Never	Not often (1-2 times per month)	Sometimes (1-2 times per week)	Often (more than 3 times per week)
a	Made me sick to my stomach; threw up; it tasted bad.				
b	Forgot.				
c	It caused me to have other physical symptoms (like headache).				
d	Got in the way of daily schedule (school); too busy.				
e	Couldn't deal with it; didn't feel like taking it; needed a break; pill fatigue.				
f	Change in living situation; moved; change in caregiver.				
g	Worried people would find out about HIV; didn't want friends asking questions; felt embarrassed.				
h	Got sick with other illnesses; wasn't feeling well (like cold, flu, stomach problem).				
i	Don't think I need it anymore; I can stay healthy without it.				
j	Family or friends don't help me remember; tell me I shouldn't take it.				
k	Nowhere to keep it at school or at work.				
l	Don't understand why I have to take it.				
m	Taking it reminds me of the HIV; just want to forget about diagnosis.				
n	Fell asleep or was still sleeping.				
o	Was away from home.				
p	Don't remember/not sure if tablets were taken.				
q	Ran out of tablets.				

Complete this section ONLY if you started taking ARVs but then stopped taking them.

9 What month and year did you STOP taking your ARVs?

☐☐/☐☐

(month) (year)

☐ Don't know/not sure

10 How did you decide to stop taking your ARV medications?

☐ I decided to stop by myself.

☐ The doctor/nurse recommended that I should stop.

☐ The doctor/nurse and I decided together that I should stop.

11 People stop taking their medication for various reasons. Please choose all the reasons why you stopped taking your HIV medication.

☐ Side-effects. Please write them down: _____

☐ My ARVs weren't working.

☐ I became tired of taking the tablets.

☐ It was too hard to take the tablets every day.

☐ Other reasons. Please write them down: _____

_____

HOW YOU ARE MANAGING YOUR TREATMENT

12 How confident are you that you can do things related to HIV? For each question, choose a number to show us how confident you are, if 1 shows that you are not at all confident and 10 shows that you are totally confident.

	How confident are you that you can...	Not at all confident				Somewhat confident					Totally confident
1	Stick to your treatment even when side-effects begin to interfere with your daily activities?	1	2	3	4	5	6	7	8	9	10
2	Make your treatment part of your daily activities?	1	2	3	4	5	6	7	8	9	10
3	Make a plan to take your treatment when you are with people who don't know you are HIV positive?	1	2	3	4	5	6	7	8	9	10
4	Stick to your treatment even when your day does not go the way you planned it or your routine changed?	1	2	3	4	5	6	7	8	9	10
5	Stick to your treatment when you aren't feeling well?	1	2	3	4	5	6	7	8	9	10
6	Continue with your treatment even when it interferes with your daily activities?	1	2	3	4	5	6	7	8	9	10
7	Continue with your treatment even when getting to your clinic appointment is really inconvenient?	1	2	3	4	5	6	7	8	9	10
8	Continue with your treatment even when you are feeling discouraged about your health?	1	2	3	4	5	6	7	8	9	10

4 YOUR CLINIC OR HOSPITAL

Please choose one option for each question about the clinic or hospital you go to for your HIV care:

1 My primary healthcare provider is:

☐ Doctor ☐ Nurse Other (please describe): _____

2 My healthcare provider treats me with respect.

☐ Always ☐ Usually ☐ Sometimes ☐ Never

3 In general, how satisfied are you with the service you receive at the clinic or hospital?

☐ Very satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very dissatisfied

4 Do you like going to the clinic or hospital?

☐ Yes ☐ No

5 Do transport problems prevent you from going to the clinic or hospital?

☐ Always ☐ Usually ☐ Sometimes ☐ Never

5 TAKING CARE OF YOURSELF

We would like to know how you take care of yourself. Think about your thoughts, feelings and actions over the PAST MONTH when you answer these questions.

	Please answer all the questions below by marking one answer for each statement.	**Strongly agree**	**Agree**	**Disagree**	**Strongly disagree**
1	I know the signs and symptoms of my illness (HIV) (for example, when I am sick or have side-effects from my ARVs).				
2	I can get information about HIV.				
3	I know the date of my next hospital or clinic appointment.				
4	I know how to contact the doctor or nurse if I need to.				
5	I can achieve as much as other people who don't have HIV.				
6	My faith helps me to stay positive about myself and my future.				
7	I am confident I can take care of my health.				
8	I would cope if I told someone about my HIV status and that person didn't accept it or ignored me.				
9	I would tell my parents or teacher if I were being bullied (physically or verbally) and it felt out of my control.				

		Always	Most of the time	Some-times	Never
10	I decide by myself whom I want to tell about my HIV status.				
11	I can cope with it if people say nasty or hurtful things about people living with HIV.				
12	Doing things I like (for example, listening to music, reading or playing sport) helps me to cope.				
13	Things like eating junk food, smoking cigarettes, drinking alcohol or taking drugs help me to cope.				
14	I aim to be independent (taking care of myself).				
15	I aim to enjoy life, feel good and have fun.				
16	I aim to be successful (for example, finishing school, studying further or getting a job).				
17	I feel confident I can meet my health and life goals.				
18	I do things to improve my health (for example, by exercising or eating healthy foods).				
19	I attend clinic appointments on my own.				
20	I attend clinic appointments on scheduled dates (for example, I use a calendar, phone or my clinic card to remind myself).				
21	I take part in decisions about my health and treatment (for example, I tell the doctor or nurse what I think and we make decisions together).				
22	I ask the doctor or nurse questions when there is anything I don't understand.				
23	I tell the doctor or nurse how I am feeling (for example, when I feel sick, depressed or have side-effects because of my treatment).				
24	I tell the doctor or nurse when I miss a dose of my ARVs.				
25	I tell the doctor or nurse about private things (for example, if I am having sex or using drugs or alcohol).				
26	My family supports me to live with HIV.				
27	The doctors, nurses and counsellors at the clinic support me to live with HIV.				
28	Other adolescents at the clinic (for example, in my support group or club) support me to live with HIV.				
29	I have regular contact with friends (for example, at school or in my community).				
30	I participate in activities at school or in my community.				

		Always	Most of the time	Some-times	Never
31	I would find help in my community if I needed it (for example, a social worker if I had problems at home or at school).				
	Answer question 32-43 if you take ARVs. If you do not take ARVs, go to question 44.	**Strongly agree**	**Agree**	**Disagree**	**Strongly disagree**
32	I understand why I am taking ARVs.				
33	I know the names of the ARVs.				
34	I know at what times I should take my ARVs.				
35	I know what to do when I miss the time to take my ARVs.				
36	I understand what will happen if I don't take my ARVs every day.				
37	I know what my viral load is.				
38	I know what my viral load should be.				
		Always	**Most of the time**	**Some-times**	**Never**
39	I rely on other people to remind me to take my ARVs				
40	Other things interfere with my plans to take ARVs (for example, when I go to a party or sleepover or when I do drugs).				
41	I plan how to take my ARVs when I am not at home (for example, when I am out with friends or go on a school camp).				
42	I aim to understand why my viral load is high or low.				
43	I take my ARVs even when I don't want to (for example, when I feel depressed or am tired of taking them).				
	Answer question 44 if you are having sex. If you are not having sex, skip the question and go to section 6.	**Always**	**Most of the time**	**Some-times**	**Never**
44	My partner and I use a condom when we have sex.				

6 YOUR LIFE EVENTS

Below are some examples of life events. Think back and then please check "Yes" or "No" to show if the event has happened to you IN THE PAST YEAR.

1	Did you get seriously injured or assaulted or threatened?	Yes	No
2	Did you stay in hospital?	Yes	No
3	Has a close relative had a serious illness, been injured or been assaulted?	Yes	No
4	Did your parent/caregiver die?	Yes	No
5	Did a close friend or relative die?	Yes	No
6	Did you or your partner break off a steady relationship?	Yes	No
7	Did you have a serious problem with a close friend, neighbour or relative?	Yes	No

8	Were there major financial problems in your family?	Yes	No
9	Did someone in your house lose her or his job?	Yes	No
10	Were you homeless or did you lose your house or did you have to move?	Yes	No
11	Did you go hungry because there wasn't enough money?	Yes	No
12	Did you have something valuable lost or stolen?	Yes	No
13	Did you or a family member have problems with the police?	Yes	No
14	Did someone abuse you sexually?	Yes	No
15	Did someone abuse you physically or verbally?	Yes	No
16	Did you abuse alcohol or drugs?	Yes	No
17	Did others reject you because you have HIV?	Yes	No
18	Did others reject members of your family because you have HIV?	Yes	No
19	Did you change schools?	Yes	No
20	Did your family situation change (for example, a family member left home, parents separated, change of caregiver, birth of new sibling, marriage of parent)?	Yes	No

7 YOUR QUALITY OF LIFE

How are you? How do you feel? This is what we would like you to tell us.
When you think of your answer please try to remember the LAST WEEK.

PHYSICAL ACTIVITIES AND HEALTH

1 In general, how is your health?

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

Think about the LAST WEEK...		Not at all	Slightly	Moderately	Very	Extremely
2	Did you feel fit and well?					
3	Were you physically active (for example, running, physical exercises, sports)?					
4	Were you able to do these physical exercises well?					
		Never	**Seldom**	**Quite often**	**Very often**	**Always**
5	Did you feel full of energy?					

GENERAL MOOD AND FEELINGS ABOUT YOURSELF

Think about the LAST WEEK...		Not at all	Slightly	Moderately	Very	Extremely
1	Did you enjoy your life?					
		Never	**Seldom**	**Quite often**	**Very often**	**Always**
2	Were you in a good mood?					
3	Did you have fun?					
4	Did you feel sad?					

		Never	Seldom	Quite often	Very often	Always
5	Did you feel so bad you didn't want to do anything?					
6	Did you feel lonely?					
7	Did you feel happy with the way you are?					

FAMILY AND FREE TIME

		Never	Seldom	Quite often	Very often	Always
1	Did you have enough free time for yourself?					
2	Were you able to do the things you wanted to do in your free time?					
3	Did your parent/caregiver(s) have enough time for you?					
4	Did your parent/caregiver(s) treat you fairly?					
5	Were you able to talk to your parent(s)/ caregiver(s) when you wanted to?					
6	Did you have enough money to do the same things as your friends?					
7	Did you have enough money for the things you needed last week?					

FRIENDS

		Never	Seldom	Quite often	Very often	Always
1	Did you spend time with your friends?					
2	Did you have fun with your friends?					
3	Did you and your friends help each other?					
4	Were you able to depend on your friends?					

SCHOOL AND LEARNING

		Not at all	Slightly	Moderately	Very	Extremely
1	Were you happy at school?					
2	Were you getting along well at school?					
		Never	**Seldom**	**Quite often**	**Very often**	**Always**
3	Were you able to pay attention in class?					
4	Did you get along well with your teachers?					

8 YOUR STRENGTHS AND DIFFICULTIES YOU HAVE

Please answer as best you can, even if you're not absolutely sure.
Think back and give your answer based on your behaviour over the LAST 6 MONTHS. Choose one option for each question.

		Not true	Somewhat true	Certainly true
1	I try to be nice to other people. I care about their feelings.			
2	I'm restless, I can't stay still for long.			
3	I get a lot of headaches, stomach aches or other sicknesses.			
4	I usually share with others (food, games, pens, etc).			
5	I get very angry and often lose my temper.			
6	I am usually on my own. I usually play alone or keep to myself.			
7	I usually do as I'm told.			
8	I worry a lot.			
9	I am helpful when someone is hurt, upset, or feeling ill.			
10	I am always fidgeting or squirming or wriggling.			
11	I have one good friend or more.			
12	I fight a lot. I can make other people do what I want.			
13	I am often unhappy, down-hearted or tearful.			
14	Other people my age generally like me.			
15	I am easily distracted. I find it difficult to concentrate.			
16	I am nervous in new situations. I easily lose confidence.			
17	I am kind to younger children.			
18	I am often accused of lying or cheating.			
19	Other children or young people pick on me or bully me.			
20	I often volunteer to help others (parents, teachers, children).			
21	I think before I do things.			
22	I take things that aren't mine from home, school or elsewhere.			
23	I get on better with adults than with people my own age.			
24	I have many fears. I am easily scared.			
25	I finish the work I am doing. My attention is good.			

9 YOUR USE OF ALCOHOL AND OTHER DRUGS

Please answer the following questions about your use of alcohol. Choose one option for each question.

1 How often do you have a drink containing alcohol?

- ☐ More than 4 times a week
- ☐ 2-4 times a month
- ☐ Never
- ☐ 2-3 times a week
- ☐ Once a month or less

If you have never used alcohol before, go to question 4.

If you have used alcohol before, please continue with this section.

2 How many drinks containing alcohol do you have on a typical day when you drink?

- ☐ 1-2
- ☐ 7-9
- ☐ 3-4
- ☐ 10 or more
- ☐ 5-6

3 How often do you have 6 or more drinks on one occasion?

- ☐ Never
- ☐ Every week
- ☐ Less than once a month
- ☐ Every day or almost every day
- ☐ Every month

YOUR USE OF DRUGS

4 How often have you used dagga in the past 3 MONTHS?

- ☐ Never
- ☐ Every day
- ☐ A few times
- ☐ Every week

5 How often have you used tik in the past 3 MONTHS?

- ☐ Never
- ☐ Every day
- ☐ A few times
- ☐ Every week

6 Have you ever used a drug by injection?

- ☐ No
- ☐ Yes. Please write down the name of the drug(s): _____

7 Have you ever used any other drugs that we didn't ask about?

- ☐ No
- ☐ Yes. Please write down the name of the drug(s): _____

8 In the past 3 MONTHS have you ever failed to perform your responsibilities (for example going to school, taking your ARVs) because you were drunk, high or hung over?

- ☐ No
- ☐ Not applicable
- ☐ Yes

9 In the past 3 MONTHS have you ever had sex without using a condom when you were drunk or high?

- ☐ No
- ☐ Not applicable
- ☐ Yes

10 YOUR SEXUAL BEHAVIOUR

The next questions are about sexual behaviour. Please answer each question as honestly as you can. Remember that your answers are private and won't be shown to anyone else, not even your parent/caregiver(s). You can skip any question you don't want to answer.

1 **Have you ever had oral sex?**

☐ No ☐ Yes

2 **Have you ever had penetrative vaginal sex? (When a boy or man puts his penis in a girl or woman's vagina)**

☐ No
☐ Yes

3 **Have you ever had penetrative anal sex? (When a boy or man puts his penis in a girl/woman or boy/man's anus)**

☐ No
☐ Yes

If your answer was 'No' or you chose not to answer questions 2 or 3 (that is, you never had vaginal or anal sex or do not want to answer questions about it) please go to section 11.

4 **How old were you when you first had penetrative vaginal or anal sex?** ☐☐ years old.
☐ I can't remember

5 **In the past 3 MONTHS, how many times have you had penetrative vaginal or anal sex?**

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ More than 5
☐ Don't know

6 **Of those times in the past 3 MONTHS that you had sex, how many times did you use a condom?**

☐ Never ☐ Every time ☐ Not applicable
☐ Sometimes ☐ Don't know
☐ Almost every time

7 **In the past 3 MONTHS, how many different partners did you have vaginal or anal sex with?**

☐ 1 ☐ More than 3 ☐ Not applicable
☐ 2 ☐ Don't know
☐ 3

8 **How long have you been in your most recent/current main sexual relationship?**

☐ Less than 1 month ☐ More than 1 year
☐ 1-6 months ☐ Don't know
☐ 7-11 months

9 **Do you worry that your sexual partner(s) will get HIV?**

☐ Yes. Please explain why: _____
☐ No. Please explain why: _____
☐ Not applicable.

10 **Did someone physically force you to have sex against your will in the past 3 MONTHS?**

☐ No
☐ Yes

11 Did you have a sexually transmitted infection (STI) (for example, a discharge from your vagina or penis, or sores on your genitals) in the past 3 MONTHS?

- ☐ No
- ☐ Yes

12 Did you or your partner use anything to keep from getting pregnant THE LAST TIME you had vaginal sex?

- ☐ No
- ☐ Yes
- ☐ I can't remember

13 What did you use?

- ☐ Male condom
- ☐ Female condom
- ☐ Birth control pills
- ☐ Injection
- ☐ Diaphragm
- ☐ Withdrawal/pull out
- ☐ Something else: _____
- ☐ Not applicable

FOR GIRLS/WOMEN

14 Have you ever been pregnant or are you pregnant now?

- ☐ Yes
- ☐ No
- ☐ Not applicable

FOR BOYS/MEN

15 Have you ever made a girl/woman pregnant?

- ☐ Yes
- ☐ No
- ☐ Not applicable

11 HOW YOU EXPERIENCE HIV STIGMA

1 Whom have you told you are HIV positive? Please mark all the answers that apply.

- ☐ Neighbours
- ☐ Friends
- ☐ Church community
- ☐ Relatives/other family members
- ☐ School teachers
- ☐ Other members of the community
- ☐ Nobody
- ☐ My sexual partner

2 After you told people you are HIV positive, were you treated differently?

- ☐ No
- ☐ Yes
- ☐ I can't remember
- ☐ Not applicable

3 The next set of questions asks about some of your experiences, feelings, and opinions about how people with HIV feel and how they are treated. Please do your best to answer each question. Make a cross in the appropriate block for each question.

Please answer all the questions below by marking one answer for each statement.		Strongly agree	Agree	Dis-agree	Strongly disagree
1	Having HIV makes me feel unclean.				
2	Having HIV makes me feel I am a bad person.				
3	Having HIV in my body feels disgusting.				
4	Most people think a person with HIV is disgusting.				
5	Most people with HIV are rejected when others find out.				

Please answer all the questions below by marking one answer for each statement.		Strongly agree	Agree	Dis-agree	Strongly disagree
6	Most people believe a person who has HIV is dirty.				
7	I am very careful about whom I tell that I have HIV.				
8	I work hard to keep my HIV a secret.				
9	People thought I was brave when I disclosed my HIV status.				
10	People are amazed that I was able to live my life so well while being HIV positive and taking ART.				

12 YOUR RESILIENCE

To what extent do the sentences below describe you? Make a cross in the appropriate block for each question.

		Not at all	A little	Somewhat	Quite a bit	A lot
1	I have people I want to be like.					
2	Getting an education is important to me.					
3	I feel my parent(s)/caregiver(s) knows a lot about me (for example, who my friends are, what I like to do).					
4	I try to finish activities I start.					
5	When things don't go my way, I can fix it without hurting myself or other people (for example not hitting others or saying nasty things).					
6	I know where to go for help.					
7	I feel that I belong at my school.					
8	I think my family cares about me when times are hard (for example when I am sick or have done something wrong).					
9	I think my friends care about me when times are hard (for example, when I am sick or have done something wrong).					
10	I am treated fairly.					
11	I have chances to learn things that will be useful when I am older (like cooking, working, and helping others).					
12	I like the way my community celebrates things (like holidays, festivals).					

For the researcher to complete

1 Latest VL in patient folder: _____ Date: _____

2 Number of missed clinic or hospital appointments in the last 6 months: _____

3 Current medication listed on prescription chart (tick off):

- ☐ Cotrimoxazole (Bactrim)
- ☐ Isoniazid (IPT)
- ☐ Combination tablets: tenofovir, emtricitabine, efavirenz (Atripla, Odimune)
- ☐ Combination tablets: abacavir, lamivudine (Kivexa)
- ☐ Efavirenz (EFV, Stocrin)
- ☐ Lopinavir/ritonavir (Kaletra/Aluvia)
- ☐ Abacavir (ABC, Ziagen)
- ☐ Atazanavir (ATV)
- ☐ Lamivudine (3TC)
- ☐ Stavudine (d4T)
- ☐ Didanosine (ddI)
- ☐ Nevirapine (NVP, Viramune)
- ☐ Zidovudine (AZT, Retrovir)
- ☐ Ritonavir (RTV)
- ☐ Darunavir (DRV)
- ☐ Raltegravir (RAL)
- ☐ AZT/3TC (Lamzid, Combivir)
- ☐ Don't know/Not sure
- ☐ Other (please write down the medication): _____

APPENDIX 10: PHASE 4 DESCRIPTIVE TABLES

Demographic details of participants: Questions about you

Variable	n (%)
Age [calculated from date of birth] (n=385)	
13	73 (19)
14	74 (19.2)
15	65 (16.9)
16	74 (19.2)
17	57 (14.8)
18	42 (10.9)
Home language (n=384)	
IsiXhosa	296 (77.1)
Afrikaans	53 (13.8)
English	25 (6.5)
Other	10 (2.6)
Gender (n=385)	
Male	159 (41.3)
Female	224 (58.2)
I choose not to say	2 (0.5)
Are you in school? (n=383)	
Yes	377 (98.4)
No	6 (1.6)
Completed appropriate grade for age? [researcher determined] (n=381)	
Yes	243 (63.8)
No	138 (36.2)
With whom do you stay? (n=383)	
Biological mother	151 (39.4)
Biological father	15 (3.9)
Biological mother and father	80 (20.8)
Family member (aunt, grandmother, sister, brother, etc.)	118 (30.6)
Adoptive parents	13 (3.4)
Other	6 (1.6)
How long have you lived with this person? (n=383)	
Less than one year	31 (8.1)
1 – 5 years	37 (9.7)
6 – 10 years	37 (9.7)
More than 10 years	278 (72.6)

Variable	n (%)
Level of education of primary caregiver (n=380)	
No formal schooling	15 (3.9)
Primary school	57 (15)
High school	150 (39.5)
College or university	38 (10)
Not sure / don't know	120 (31.6)
Is your biological mother still alive? (n=383)	
Yes	267 (69.7)
No	106 (27.7)
Not sure	10 (2.6)
Is your biological father still alive? (n=379)	
Yes	231 (60.9)
No	121 (31.9)
Not sure	27 (7.1)
Are you still in contact with your biological mother and father? (n=383)	
Yes, with my mother and father	131 (34.2)
Yes, only with my mother	127 (33.2)
Yes, only with my father	40 (10.4)
No	85 (22.2)
Number of people in the same house as you (n=363)	
Median (Interquartile range)	4 (3)
Number of times moved house in the past 5 years (n=376)	
Median (Interquartile range)	1 (2)
Nights stayed away from home in the past week (n=375)	
Median (Interquartile range)	0 (1)
When were you diagnosed with HIV? (n=383)	
At birth	192 (50.1)
Before the age of 6	33 (8.6)
Between 6 and 12	33 (8.6)
After the age of 12	56 (14.6)
Don't know / not sure	69 (18)
At what age did you find out you were HIV positive? (n=375)	
Between the ages of 6 and 10	159 (42.4)
Between the ages of 10 and 12	97 (25.9)
After the age of 12	119 (31.7)
Do you have other conditions or illnesses? (n=384)	
Yes	52 (13.5)
No	309 (80.5)
I don't know	23 (6)

Variable	n (%)
How did you become infected with HIV? [More than one option could be selected]	
At birth/from my mother	282 (73.2)
By having sex	46 (11.9)
Forced sex or abuse	11 (2.9)
Shared needles or recreational drug equipment	8 (2.1)
Blood transfusion or other medical procedure	19 (4.9)
Don't know	94 (24.4)
Most likely route of infection [researcher determined]	
Perinatally or early in life	344 (89.4)
Behaviourally	41 (10.6)

Your symptoms

Symptom	I don't have this symptom n (%)	It doesn't bother me n (%)	It bothers me a little n (%)	It bothers me a lot n (%)
a) Tiredness or loss of energy **(n=380)**	182 (47.9)	53 (13.9)	113 (29.7)	32 (8.4)
b) Dizziness and light headedness **(n=380)**	154 (40.5)	59 (15.5)	119 (31.3)	48 (12.6)
c) Forgetfulness **(n=380)**	154 (40.5)	65 (17.1)	105 (27.6)	56 (14.7)
d) Nausea, vomiting or stomach pain **(n=378)**	190 (50.3)	52 (13.8)	88 (23.3)	48 (12.7)
e) Feeling sad, down or depressed **(n=382)**	171 (44.8)	61 (15.8)	99 (25.9)	51 (13.4)
f) Nervousness or anxiousness **(n=380)**	187 (48.6)	72 (18.9)	94 (24.7)	27 (7.1)
g) Difficulty falling asleep or staying asleep **(n=381)**	180 (47.2)	64 (16.8)	87 (22.8)	50 (13.1)
h) Skin problems… **(n=381)**	174 (45.7)	43 (11.4)	88 (23.1)	76 (19.9)
i) Coughing or trouble catching your breath **(n=379)**	178 (47)	59 (15.6)	90 (23.7)	52 (13.7)
j) Headaches **(n=377)**	140 (37.1)	60 (15.9)	119 (30.8)	61 (16.2)
k) Not feeling hungry or changes in taste… **(n=376)**	200 (53.2)	67 (17.8)	74 (19.7)	35 (9.3)
l) Muscle aches or joint pains **(n=380)**	198 (52.1)	64 (16.8)	85 (22.4)	33 (8.7)
	Mean	**SD**	**Min**	**Max**
Total symptoms (n=358)	12.53	7.64	0	33

Your treatment

Variable	n (%)
How long have you been taking ARVs? (n=375)	
Less than 1 year	51 (13.6)
1-5 years	66 (17.6)
6-10 years	69 (18.4)
More than 10 years	121 (32.3)
Don't know / not sure	68 (18.1)

Variable	n (%)
How many tablets do you have to take every day? (n=373)	
1	100 (26.8)
2	110 (26.8)
3	86 (23.1)
More than 3	68 (18.2)
Don't know / not sure	9 (2.4)
How often do you have to take your tablets? (n=376)	
Once a day	236 (62.8)
Twice a day	121 (32.2)
More than two times a day	14 (3.7)
Don't know / not sure	5 (1.3)
When was the last time that you missed taking any of your ARVs? (n=376)	
Within the past week	117 (31.1)
1-2 weeks ago	52 (13.8)
2-4 weeks ago	14 (3.7)
1-3 months ago	20 (5.3)
More than 3 months ago	30 (8)
Never skip medication / not applicable	143 (38)
In general, over the past month, how often did you miss taking your ARVs? (n=375)	
I hardly ever take any of my ARVs	5 (1.3)
I miss most of my ARVs	14 (3.7)
I miss about half of my ARVs	17 (4.5)
I miss my ARVs a little bit of the time	171 (45.6)
I never miss any of my ARVs	168 (44.8)
How many times did you miss taking your ARVs in the last week? (n=370)	
Median (Interquartile range)	0 (2)

Your treatment: Barriers to adherence

Reasons for missing ARV's over the past month	Never n %	Not often n %	Sometimes n %	Often n %
a) Made me sick to my stomach; threw up; it tasted bad **(n=371)**	274 (73.9)	36 (9.7)	45 (12.1)	16 (4.3)
b) Forgot **(n=372)**	176 (47.3)	83 (22.3)	88 (22.3)	25 (6.7)
c) It caused me to have other problems (like headaches) **(n=371)**	263 (70.9)	48 (12.9)	36 (9.7)	24 (6.5)
d) Got in the way of daily schedule (school); too busy **(n=372)**	273 (73.4)	32 (8.6)	56 (15.1)	11 (3)
e) Couldn't deal with it; didn't feel like taking it… **(n=373)**	280 (75.1)	31 (8.3)	42 (11.3)	20 (5.4)
f) Change in living situation; moved; change in caregiver **(n=370)**	302 (81.6)	35 (9.5)	21 (5.7)	12 (3.2)
g) Worried people would find out about HIV… **(n=370)**	260 (70.3)	33 (8.9)	44 (14.9)	22 (5.9)
h) Got sick with other illnesses; wasn't feeling well…**(n=365)**	248 (67.9)	52 (14.2)	42 (11.5)	23 (6.3)
i) Don't think I need it anymore; I can stay healthy without it **(n=371)**	290 (78.2)	35 (9.4)	35 (9.4)	11 (3)
j) Family or friends don't help me remember… **(n=370)**	281 (75.9)	31 (8.4)	30 (8.1)	28 (7.6)

Reasons for missing ARV's over the past month	Never n %	Not often n %	Sometimes n %	Often n %
k) Nowhere to keep it at school or at work **(n=370)**	314 (84.9)	27 (7.3)	24 (6.5)	5 (1.4)
l) Don't understand why I have to take it **(n=370)**	291 (78.6)	23 (6.2)	32 (8.6)	24 (6.5)
m) Taking it reminds me of the HIV; just want to forget… **(n=371)**	247 (66.6)	46 (12.4)	47 (12.7)	31 (8.4)
n) Fell asleep or was still sleeping **(n=373)**	238 (63.8)	58 (15.5)	60 (16.1)	17 (4.6)
o) Was away from home **(n=375)**	254 (67.7)	49 (13.1)	54 (14.4)	18 (4.8)
p) Don't remember/not sure if tablets were taken **(n=373)**	277 (74.3)	41 (11)	42 (11.3)	13 (3.5)
q) Ran out of tablets **(n=372)**	299 (80.4)	28 (7.5)	34 (9.1)	11 (3)
	Median	**IQR**	**Min**	**Max**
Total reasons for missing treatment (n=339)	6	12	0	34

Your treatment: Treatment self-efficacy

How you are managing your treatment			
How confident are you that you can….	**n**	**Mean**	**SD**
1. Stick to your treatment even when side-effects begin to interfere with your daily activities?	377	7.57	3.2
2. Make your treatment part of your daily activities?	375	7.98	2.9
3. Make a plan to take your treatment when you are with people who don't know…?	373	7.36	3.4
4. Stick to your treatment even when your day does not go the way you planned…?	376	7.57	3.1
5. Stick to your treatment when you aren't feeling well?	373	8.12	2.8
6. Continue with your treatment even when it interferes with your daily activities?	374	8.13	2.8
7. Continue with your treatment even when getting to your clinic appointment is really inconvenient?	376	7.86	2.8
8. Continue with your treatment even when you are feeling discouraged about your health?	375	7.82	3.1

Your treatment: Regimen, viral load and missed visits

Variable	n (%)
Current regimen (n=377)	
ABC, 3TC, EFV	132 (35)
TDF, FTC, EFV (FDC)	94 (24.9)
AZT, 3TC, LPV/r	52 (13.8)
ABC, 3TC, LPV/r	48 (12.7)
Other (7 participants or less per individual regimen)	51 (13.6)
Viral load log value (n=348)	
Median (Interquartile range)	0 (2)
Viral load (n=347)	
Suppressed (< 400)	285 (82.1)
Not suppressed (> 400)	62 (17.9)
Number of missed clinic/hospital visits in the last 6 months (n=332)	
Median (Interquartile range)	0 (0)

Your clinic or hospital

Variable	n (%)		n (%)
My primary healthcare provider is (n=380)		**My healthcare provider treats me with respect (n=384)**	
Doctor	241 (63.4)	Always	301 (78.4)
Nurse	134 (35.3)	Usually	48 (12.5)
Other	5 (1.3)	Sometimes	29 (7.6)
		Never	6 (1.6)
In general, how satisfied are you with the service you receive at the clinic or hospital? (n=383)		**Do transport problems prevent you from going to the clinic or hospital? (n=383)**	
Very satisfied	245 (64)	Always	44 (11.5)
Satisfied	107 (27.9)	Usually	28 (7.3)
Dissatisfied	16 (4.2)	Sometimes	105 (27.4)
Very dissatisfied	15 (3.9)	Never	206 (53.8)

Variable	n (%)
Do you like coming to the clinic? (n=384)	
Yes	286 (74.5)
No	98 (25.5)

Taking care of yourself (AdHIVSM measure)

Variable	Strongly agree/ Always n (%)	Agree/ Most of the time n (%)	Disagree/ Sometimes n (%)	Strongly disagree/ Never n (%)	Mean (SD)
1. I know the signs and symptoms of my illness (HIV) … **(n=384)**	129 (33.6)	161 (41.9)	76 (19.8)	18 (4.7)	3.04 0.85)
2. I can get information about HIV **(n=384)**	281 (56.8)	136 (35.4)	17 (4.4)	13 (3.4)	3.46 0.74)
3. I know the date of my next clinic appointment **(n=384)**	258 (67.2)	94 (24.5)	18 (4.7)	14 (3.6)	3.55 (0.75)
4. I know how to contact the doctor or nurse… **(n=384)**	158 (41.1)	138 (35.9)	60 (15.6)	28 (7.3)	3.11 (0.92)
5. I can achieve as much as other people… **(n=384)**	251 (65.4)	96 (25)	21 (5.5)	16 (4.2)	3.52 (0.78)
6. My faith helps me to stay positive… **(n=385)**	271 (70.4)	96 (24.9)	11 (2.9)	7 (1.8)	3.64 (0.63)
7. I am confident I can take care of my health **(n=385)**	270 (70.1)	92 (23.9)	15 (3.9)	8 (2.1)	3.62 (0.66)
8. I would cope if I told someone about my HIV status…**(n=384)**	96 (25)	102 (26.6)	108 (28.1)	78 (20.3)	2.56 (1.08)
9. I would tell my parents or teacher… **(n=385)**	180 (46.8)	130 (33.8)	42 (10.9)	33 (8.6)	3.19 (0.94)
10. I decide by myself whom I want to tell…**(n=383)**	149 (38.9)	66 (17.2)	67 (17.5)	101 (26.4)	2.69 (1.24)
11. I can cope with it if people say nasty…(**n=384)**	94 (24.5)	69 (18)	104 (27.1)	117 (30.5)	2.36 (1.16)
12. Doing things I like helps me to cope **(n=384)**	257 (66.9)	73 (19)	35 (9.1)	19 (4.9)	3.48 (0.86)
13. Things like eating junk food… **(n=383) [Reverse scored item]**	30 (7.8)	22 (5.7)	34 (8.9)	297 (77.5)	3.56 (0.91)
14. I aim to be independent (taking care of myself) **(n=384)**	245 (63.6)	65 (16.9)	37 (9.6)	37 (9.6)	3.35 (1)
15. I aim to enjoy life, feel good and have fun **(n=383)**	279 (72.8)	59 (15.4)	35 (9.1)	10 (2.6)	3.58 (0.76)
16. I aim to be successful… **(n=385)**	317 (82.3)	46 (11.9)	14 (3.6)	8 (2.1)	3.75 (0.62)
17. I feel confident I can meet my health and life goals **(n=385)**	286 (74.3)	61 (15.8)	24 (6.2)	14 (3.6)	3.61 (0.76)
18. I do things to improve my health… **(n=385)**	237 (61.6)	78 (20.3)	62 (16.1)	8 (2.1)	3.41 (0.83)

Variable	Strongly agree/ Always n (%)	Agree/ Most of the time n (%)	Disagree/ Sometimes n (%)	Strongly disagree/ Never n (%)	Mean (SD)
19. I attend clinic appointments on my own **(n=382)**	180 (47.1)	53 (13.9)	70 (18.3)	79 (20.7)	2.87 (1.21)
20. I attend clinic appointments on scheduled dates … **(n=382)**	250 (65.4)	69 (18.1)	43 (11.3)	20 (5.2)	3.44 (0.89)
21. I take part in decisions about my health…**(n=383)**	160 (41.6)	71 (18.4)	89 (23.2)	63 (16.4)	2.86 (1.14)
22. I ask the doctor or nurse questions when…**(n=383)**	192 (49.9)	65 (17)	97 (25.3)	29 (7.6)	3.1 (1.03)
23. I tell the doctor or nurse how I am feeling… **(n=382)**	190 (49.7)	74 (19.4)	82 (21.5)	36 (9.4)	3.09 (1.04)
24. I tell the doctor or nurse when I miss a dose… **(n=384)**	129 (33.5)	64 (16.6)	81 (21.1)	110 (28.6)	2.55 (1.22)
25. I tell the doctor or nurse about private things… **(n=383)**	97 (25.3)	39 (10.2)	69 (18)	178 (46.5)	2.14 (1.25)
26. My family supports me to live with HIV **(n=384)**	300 (78.1)	35 (9.1)	25 (6.5)	24 (6.3)	3.59 (0.86)
27. The doctors, nurses and counsellors at the clinic… **(n=384)**	289 (75.3)	43 (11.2)	38 (9.9)	14 (3.6)	3.58 (0.81)
28. Other adolescents at the clinic support me… **(n=384)**	213 (55.5)	66 (17.2)	48 (12.5)	57 (14.8)	3.13 (1.12)
29. I have regular contact with friends… **(n=384)**	191 (49.7)	67 (17.4)	60 (15.6)	66 (17.2)	3 (1.16)
30. I participate in activities at school… **(n=385)**	182 (47.3)	57 (14.8)	95 (24.7)	51 (13.2)	2.96 (1.12)
31. I would find help in my community if I needed it… **(n=381)**	160 (42)	75 (19.7)	80 (21)	66 (17.3)	2.86 (1.14)
32. I understand why I am taking ARVs **(n=376)**	266 (70.7)	79 (21)	20 (5.3)	11 (2.9)	3.6 (0.72)
33. I know the names of the ARVs **(n=376)**	102 (27.1)	112 (29.8)	120 (31.9)	42 (11.2)	2.73 (0.98)
34. I know at what times I should take my ARVs **(n=374)**	275 (73.5)	89 (23.8)	6 (1.6)	4 (1.1)	3.7 (0.56)
35. I know what to do when I miss the time…**(n=377)**	177 (46.9)	119 (31.6)	61 (16.2)	20 (5.3)	3.2 (0.89)
36. I understand what will happen if I don't take my… **(n=375)**	245 (65.3)	83 (22.1)	32 (8.5)	15 (4)	3.49 (0.81)
37. I know what my viral load is **(n=376)**	88 (23.4)	89 (23.7)	135 (35.9)	64 (17)	2.53 (1.03)
38. I know what my viral load should be **(n=376)**	119 (31.6)	82 (21.8)	114 (30.3)	61 (16.2)	2.69 (1.08)
39. I rely on other people… **(n=377) [Reverse scored item]**	75 (19.9)	47 (12.5)	102 (27.1)	153 (40.6)	2.88 (1.15)
40. Other things interfere…**(n=377) [Reverse scored item]**	34 (9)	38 (10.1)	86 (22.8)	219 (58.1)	3.3 (0.98)
41. I plan how to take my ARVs when I am not at home… **(n=362)**	175 (48.3)	69 (19.1)	75 (20.7)	43 (11.9)	3.04 (1.08)
42. I aim to understand why my viral load is high or low **(n=374)**	141 (37.7)	83 (22.2)	87 (23.3)	63 (16.8)	2.81 (1.12)
43. I take my ARVs even when I don't want to… **(n=377)**	221 (58.6)	39 (10.3)	55 (14.6)	62 (16.4)	3.11 (1.18)
44. My partner and I use a condom when we have sex **(n=120)**	73 (60.8)	15 (12.5)	21 (17.5)	11 (9.2)	3.25 (1.05)

Life Events

Variable	Yes n (%)	No n (%)
1. Did you get seriously injured or assaulted or threatened? **(n=383)**	110 (28.7)	273 (71.3)
2. Did you stay in hospital? **(n=384)**	124 (32.2)	260 (67.7)
3. Has a close relative had a serious illness, been injured or been assaulted? **(n=385)**	120 (31.2)	265 (68.8)
4. Did your parent/caregiver die? **(n=384)**	109 (28.4)	275 (71.6)
5. Did a close friend or relative die? **(n=384)**	126 (32.7)	258 (67.2)
6. Did you or your partner break off a steady relationship? **(n=377)**	103 (27.3)	274 (72.7)
7. Did you have a serious problem with a close friend, neighbour or relative? **(n=384)**	98 (25.5)	286 (74.5)
8. Were there major financial problems in your family? **(n=383)**	145 (37.9)	238 (62.1)
9. Did someone in your house lose her or his job? **(n=384)**	156 (40.6)	228 (59.4)

Variable	Yes n (%)	No n (%)
10. Were you homeless or did you lose your house or did you have to move? **(n=382)**	48 (12.5)	334 (87.4)
11. Did you go hungry because there wasn't enough money? **(n=385)**	115 (29.9)	270 (70.1)
12. Did you have something valuable lost or stolen? **(n=385)**	131 (34)	254 (66)
13. Did you or a family member have problems with the police? **(n=385)**	62 (16.1)	323 (83.9)
14. Did someone abuse you sexually? **(n=385)**	25 (6.5)	360 (93.5)
15. Did someone abuse you physically or verbally? **(n=385)**	59 (15.3)	326 (84.7)
16. Did you abuse alcohol or drugs? **(n=383)**	45 (11.7)	338 (88.3)
17. Did others reject you because you have HIV? **(n=383)**	46 (12)	337 (88)
18. Did others reject members of your family because you have HIV? **(n=383)**	38 (9.9)	345 (90.1)
19. Did you change schools? **(n=384)**	133 (34.6)	251 (65.4)
20. Did your family situation change…? **(n=385)**	97 (25.2)	288 (74.8)

Health-Related Quality of Life (KIDSCREEN-27)

Physical Activities and Health					
	Excellent n (%)	**Very good n (%)**	**Good n (%)**	**Fair n (%)**	**Poor n (%)**
1. In general, how is your health? **(n=383)**	149 (38.9)	126 (32.9)	79 (20.6)	22 (5.7)	7 (1.8)
In the past WEEK…	**Not at all/Never n (%)**	**Slightly/ Seldom n (%)**	**Moderately/ Quite often n (%)**	**Very/ Very often n (%)**	**Extremely/ Always n (%)**
2. Did you feel fit and well? **(n=385)**	52 (13.5)	61 (15.8)	28 (7.3)	159 (41.3)	85 (22.1)
3. Were you physically active…? **(n=382)**	66 (17.3)	54 (14.1)	52 (13.6)	126 (33)	84 (22)
4. Were you able to do these physical exercises…? **(n=383)**	51 (13.3)	61 (15.9)	41 (10.7)	138 (36)	92 (24)
5. Did you feel full of energy? **(n=380)**	27 (7.1)	48 (12.6)	73 (19.2)	99 (26.1)	133 (35)
General Mood and Feelings					
6. Did you enjoy your life? **(n=380)**	22 (5.8)	34 (8.9)	31 (8.2)	171 (45)	122 (32.1)
7. Were you in a good mood? **(n=385)**	22 (5.7)	47 (12.2)	64 (16.6)	117 (30.4)	135 (35.1)
8. Did you have fun? **(n=382)**	29 (7.6)	26 (6.8)	51 (13.4)	95 (24.9)	181 (47.4)
9. Did you feel sad? **(n=383) [Reverse scored (RS) item]**	193 (50.4)	67 (17.5)	69 (18)	33 (8.6)	21 (5.5)
10. Did you feel so bad you didn't want to…? **(n=382) [RS]**	199 (52.1)	55 (14.4)	78 (20.4)	29 (7.6)	21 (5.5)
11. Did you feel lonely? **(n=382) [RS]**	210 (55)	58 (15.2)	53 (13.9)	37 (9.7)	24 (6.3)
12. Did you feel happy with the way you are? **(n=384)**	35 (9.1)	40 (10.4)	44 (11.5)	85 (22.1)	180 (46.9)
Family and Free Time					
13. Did you have enough free time for yourself? **(n=384)**	29 (7.6)	31 (8.1)	61 (15.9)	103 (26.8)	160 (41.7)
14. Were you able to do the things you wanted…? **(n=382)**	34 (8.9)	41 (10.7)	63 (16.5)	95 (24.9)	149 (39)
15. Did your parent/caregiver(s) have enough…? **(n=374)**	39 (10.4)	24 (6.4)	47 (12.6)	82 (21.9)	182 (48.7)
16. Did your parent/caregiver(s) treat you fairly? **(n=379)**	42 (11.1)	24 (6.3)	52 (13.7)	70 (18.5)	191 (50.4)
17. Were you able to talk to your parent(s)…? **(n=384)**	36 (9.4)	28 (7.3)	56 (14.6)	78 (20.3)	186 (48.4)
18. Did you have enough money…? **(n=384)**	110 (28.6)	70 (18.2)	78 (20.3)	53 (13.8)	73 (19)
19. Did you have enough money for the things…? **(n=385)**	103 (26.8)	73 (19)	75 (19.5)	58 (15.1)	76 (19.7)

In the past WEEK…	Not at all/Never n (%)	Slightly/ Seldom n (%)	Moderately/ Quite often n (%)	Very/ Very often n (%)	Extremely/ Always n (%)
Friends					
20. Did you spend time with your friends? **(n=385)**	41 (10.6)	43 (11.2)	62 (16.1)	81 (21)	158 (41)
21. Did you have fun with your friends? **(n=382)**	30 (7.8)	26 (6.8)	62 (16.2)	79 (20.7)	185 (48.4)
22. Did you and your friends help each other? **(n=383)**	26 (6.8)	26 (6.8)	57 (14.9)	88 (23)	186 (48.6)
23. Were you able to depend on your friends? **(n=383)**	111 (29)	56 (14.6)	56 (14.6)	69 (18)	91 (23.8)
School and Learning					
24. Were you happy at school? **(n=373)**	21 (5.6)	23 (6.2)	20 (5.4)	170 (45.6)	139 (37.3)
25. Were you getting along well at school? **(n=375)**	18 (4.8)	38 (10.1)	21 (5.6)	161 (42.9)	137 (36.5)
26. Were you able to pay attention in class? **(n=375)**	22 (5.9)	29 (7.7)	59 (15.7)	107 (28.5)	158 (42.1)
27. Did you get along well with your teachers? **(n=376)**	6 (1.6)	29 (7.7)	47 (12.5)	108 (28.7)	186 (49.5)

Strengths and Difficulties

	Not true n (%)	Somewhat true n (%)	Certainly true n (%)
1. I try to be nice to other people. I care about… **(n=384) {Prosocial scale}**	33 (8.6)	139 (36.2)	212 (55.2)
2. I'm restless, I can't stay still for long **(n=383)**	168 (43.9)	123 (32.1)	92 (24)
3. I get a lot of headaches, stomach aches or… **(n=383) {Prosocial scale}**	227 (59.3)	102 (26.6)	54 (14.1)
4. I usually share with others (food, games, pens, etc) **(n=384)**	55 (14.3)	108 (28.1)	221 (57.6)
5. I get very angry and often lose my temper **(n=382)**	173 (45.3)	123 (32.2)	86 (22.5)
6. I am usually on my own. I usually play alone or keep to myself **(n=384)**	229 (59.6)	90 (23.4)	65 (16.9)
7. I usually do as I'm told **(n=381) [Reverse scored]**	75 (19.7)	145 (38.1)	161 (42.3)
8. I worry a lot **(n=383)**	160 (41.8)	134 (35)	89 (23.2)
9. I am helpful when someone is hurt, upset, or feeling ill **(n=384) {Prosocial scale}**	56 (14.6)	135 (35.2)	193 (50.3)
10. I am always fidgeting or squirming or wriggling **(n=378)**	191 (50.5)	143 (37.8)	44 (11.6)
11. I have one good friend or more **(n=383) [Reverse scored]**	62 (16.2)	101 (26.4)	219 (57.3)
12. I fight a lot. I can make other people do what I want **(n=380)**	306 (80.5)	48 (12.6)	26 (6.8)
13. I am often unhappy, down-hearted or tearful **(n=382)**	251 (65.7)	95 (24.9)	36 (9.4)
14. Other people my age generally like me **(n=383) [Reverse scored]**	45 (11.7)	143 (37.3)	195 (50.9)
15. I am easily distracted. I find it difficult to concentrate **(n=381)**	155 (40.3)	154 (40)	72 (18.9)
16. I am nervous in new situations. I easily lose confidence **(n=382)**	149 (39)	150 (39.3)	83 (21.7)
17. I am kind to younger children **(n=384) {Prosocial scale}**	43 (11.2)	100 (26)	241 (62.8)
18. I am often accused of lying or cheating **(n=382)**	242 (63.4)	88 (23)	52 (13.6)
19. Other children or young people pick on me or bully me **(n=382)**	270 (70.7)	73 (19.1)	39 (10.2)
20. I often volunteer to help others… **(n=382) {Prosocial scale}**	52 (13.6)	172 (45)	158 (41.4)
21. I think before I do things **(n=378) [Reverse scored]**	42 (11.1)	128 (33.9)	208 (55)
22. I take things that aren't mine from home, school or elsewhere **(n=382)**	269 (70.4)	83 (21.7)	30 (7.9)
23. I get on better with adults than with people my own age **(n=383)**	118 (30.8)	147 (38.4)	118 (30.8)
24. I have many fears. I am easily scared **(n=380)**	202 (53.2)	125 (32.9)	53 (13.9)
25. I finish the work I am doing. My attention is good **(n=384) [Reverse scored]**	36 (9.4)	139 (36.2)	209 (54.4)

Alcohol and drug use

Use of alcohol/drugs	n (%)
How often do you have a drink containing alcohol? (n=375)	
More than 4 times per week	3 (0.8)
2-3 times per week	8 (2.1)
2-4 times per month	16 (4.3)
Once a month or less	89 (23.7)
Never	259 (69.1)
How many drinks containing alcohol do you have on a typical day when you drink? (n=125)	
1-2	61 (48.8)
3-4	19 (15.2)
5-6	22 (17.6)
7-9	11 (8.8)
10 or more	12 (9.6)
How often do you have 6 or more drinks on one occasion? (n=123)	
Never	46 (37.4)
Less than once a month	53 (43.1)
Every month	14 (11.4)
Every week	6 (4.9)
Every day or almost every day	4 (3.3)
How often have you used dagga (cannabis) in the past 3 MONTHS? (n=374)	
Never	356 (95.2)
A few times	14 (3.7)
Every week	1 (0.3)
Every day	3 (0.8)
How often have you used tik (crystal methamphetamine) in the past 3 MONTHS? (n=373)	
Never	367 (98.4)
A few times	4 (1.1)
Every day	2 (0.5)
In the past 3 MONTHS have you ever had sex without using a condom when you were drunk or high? (n=375)	
No	90 (23.9)
Yes	14 (3.7)
Not applicable	272 (72.3)
In the past 3 MONTHS have you ever failed to perform your responsibilities (for example going to school, taking your ARVs) because you were drunk, high or hung over? (n=376)	
No	88 (23.5)
Yes	11 (2.9)
Not applicable	276 (73.6)

Sexual behaviour

Sexual behaviour	n (%)
Have you ever had oral sex? (n=379)	
No	334 (88.1)
Yes	45 (11.9)
Have you ever had penetrative vaginal sex? (n=378)	
No	257 (68)
Yes	121 (32)
Have you ever had penetrative anal sex? (n=377)	
No	351 (93.1)
Yes	26 (6.9)
How old were you the first time you had penetrative vaginal or anal sex? (n=91)	
Mean (SD)	14.03 (2.14)
Range	7 - 18
In the past 3 months, how many times you had penetrative vaginal or anal sex? (n=130)	
0	31 (23.8)
1	20 (15.4)
2	26 (20)
3	17 (13.8)
More than 5	18 (13.8)
Don't know	18 (13.8)
Of those times in the past 3 MONTHS that you had sex, how many times did you use a condom? (n=129)	
Never	20 (15.5)
Sometimes	20 (15.5)
Almost every time	17 (13.2)
Every time	52 (40.3)
Don't know	6 (4.7)
Not applicable	14 (10.9)
In the past 3 MONTHS, how many different partners did you have vaginal or anal sex with? (n=130)	
1	59 (45.4)
2	18 (13.8)
3	7 (5.4)
More than 3	5 (3.8)
Don't know	14 (10.8)
Not applicable	27 (20.8)
How long have you been in your most recent/current main sexual relationship? (n=128)	
Less than 1 month	21 (16.4)
1-6 months	24 (18.8)
7-11 months	12 (9.4)
More than 1 year	50 (39.1)
Don't know	21 (16.4)

Sexual behaviour	n (%)
Do you worry that your sexual partner(s) will get HIV? (n=1280	
Yes	65 (50.8)
No	48 (37.5)
Did someone physically force you to have sex against your will in the past 3 MONTHS? (n=129)	
Yes	5 (3.9)
No	124 (96.1)
Did you have a sexually transmitted infection (STI) in the past 3 MONTHS? (n=132)	
Yes	17 (12.9)
No	115 (87.1)
Did you or your partner use anything to keep from getting pregnant THE LAST TIME you had vaginal sex? (n=129)	
Yes	83 (64.3)
No	32 (24.8)
I can't remember	14 (10.9)
What did you use as prevention? (n=128)	
Male condom	94 (73.4)
Female condom	6 (4.7)
Birth control pills	2 (1.6)
Injection	9 (7.0)
Withdrawal/pull out	1 (0.8)
Not applicable	16 (12.5)
What did you use as prevention? (Second prevention method indicated) (n=4)	
Injection	5 (100)
For girls: Have you ever been pregnant or are you pregnant now? (n=72)	
Yes	9 (12.5)
No	59 (81.9)
Not applicable	4 (5.6)
For boys: Have you ever made a girl/woman pregnant? (n=58)	
Yes	9 (15.5)
No	44 (75.9)
Not applicable	5 (8.6)

Disclosure and stigma

	Yes n (%)	No n (%)
Whom have you told you are HIV positive? [Please mark all the answers that apply]		
Neighbours **(n=380)**	13 (3.4)	367 (96.6)
Friends **(n=379)**	30 (7.9)	349 (92.1)
Church community **(n=379)**	12 (3.2)	367 (96.8)
Relatives/other family members **(n=379)**	157 (41.4)	222 (58.6)
School teachers **(n=379)**	45 (11.9)	334 (88.1)
Other members of the community **(n=379)**	28 (7.4)	351 (92.6)

	Yes n (%)	No n (%)
My sexual partner **(n=379)**	14 (3.7)	365 (96.3)
Nobody **(n=379)**	120 (31.7)	259 (68.3)
After you told people you are HIV positive, were you treated differently? (n=371)	**n (%)**	
Yes	43 (11.6)	
No	202 (54.4)	
I can't remember	15 (4.0)	
Not applicable	111 (29.9)	

HIV Stigma Scale	**Strongly disagree n (%)**	**Disagree n (%)**	**Agree n (%)**	**Strongly agree n (%)**
1. Having HIV makes me feel unclean **(n=383)**	127 (33.2)	144 (37.6)	59 (15.4)	53 (13.8)
2. Having HIV makes me feel I am a bad person **(n=381)**	149 (39.1)	146 (38.3)	52 (13.6)	34 (8.9)
3. Having HIV in my body feels disgusting **(n=381)**	145 (38.1)	143 (37.5)	48 (12.6)	45 (11.8)
4. Most people think a person with HIV is disgusting **(n=381)**	78 (20.5)	83 (21.8)	113 (29.7)	107 (28.1)
5. Most people with HIV are rejected when others find out (n=382)	57 (14.9)	88 (23)	139 (36.4)	98 (25.7)
6. Most people believe a person who has HIV is dirty **(n=380)**	66 (17.4)	97 (25.5)	128 (33.7)	89 (23.4)
7. I am very careful about whom I tell that I have HIV **(n=381)**	28 (7.3)	46 (12.1)	109 (28.6)	198 (52)
8. I work hard to keep my HIV a secret **(n=381)**	42 (11)	44 (11.5)	122 (32)	173 (45.4)
9. People thought I was brave when I disclosed my HIV status **(n=374) [Reverse scored]**	55 (14.3)	86 (23)	122 (32.6)	111 (29.7)
10. People are amazed that I was able to live my life so well while being HIV positive and taking ART **(n=376) [Reverse scored]**	38 (9.9)	56 (14.9)	126 (33.5)	156 (41.5)

Resilience

	Not at all n (%)	**A little n (%)**	**Somewh at n (%)**	**Quite a bit n (%)**	**A lot n (%)**
1. I have people I want to be like **(n=384)**	**60 (15.6)**	**71 (18.5)**	53 (13.8)	55 (14.3)	145 (37.8)
2. Getting an education is important to me **(n=383)**	14 (3.7)	19 (5)	16 (4.2)	20 (5.2)	314 (82)
3. I feel my parent(s)/caregiver(s) knows a lot**… (n=383)**	18 (4.7)	34 (8.9)	36 (9.4)	48 (12.5)	247 (64.5)
4. I try to finish activities I start **(n=384)**	10 (2.6)	33 (8.6)	47 (12.2)	88 (22.9)	206 (53.6)
5. When things don't go my way, I can fix it… **(n=384)**	**81 (21.1)**	**35 (9.1)**	40 (10.4)	75 (19.5)	153 (39.8)
6. I know where to go for help **(n=383)**	9 (2.3)	39 (10.2)	22 (5.7)	63 (16.4)	250 (65.3)
7. I feel that I belong at my school **(n=381)**	22 (5.8)	27 (7.1)	19 (5)	61 (16)	252 (66.1)
8. I think my family cares about me when times… **(n=384)**	18 (4.7)	22 (5.7)	20 (5.2)	54 (14.1)	270 (70.3)
9. I think my friends care about me when times… **(n=382)**	**32 (8.4)**	**50 (13.1)**	46 (12)	80 (20.9)	174 (45.5)
10. I am treated fairly **(n=383)**	37 (9.7)	23 (6)	23 (6)	56 (14.6)	244 (63.7)
11. I have chances to learn things that will be useful… **(n=384)**	20 (5.2)	21 (5.5)	26 (6.8)	56 (14.6)	261 (68)
12. I like the way my community celebrates things… **(n=384)**	28 (7.3)	38 (9.9)	46 (12)	87 (22.7)	185 (48.2)

APPENDIX 11: PARALLEL ANALYSIS

Comparison of eigenvalues for PCA and criterion values from Monte Carlo parallel analysis

Component number	Actual eigenvalue from PCA	Criterion value from Monte Carlo parallel analysis	Decision	Cumulative Percentage of variance explained
1	6.337	1.6995	Accept	14.738
2	2.827	1.6236	Accept	21.312
3	2.243	1.5668	Accept	26.528
4	1.746	1.5148	Accept	30.589
5	1.676	1.4700	Accept	34.485
6	1.538	1.4305	Accept	38.061
7	1.359	1.3924	Reject	41.221

APPENDIX 12: DECLARATION BY LANGUAGE EDITOR

Mary A. Cohen
Language Practitioner

Editing and proof reading for academics

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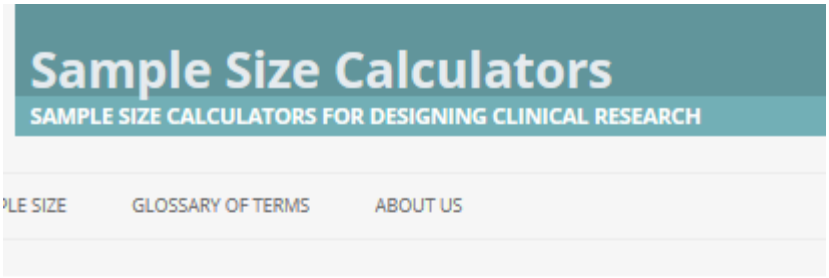
12 October 2017

Mrs Talitha Crowley
Stellenbosch University
Faculty of Medicine and Health Sciences
Department of Nursing and Midwifery

The dissertation titled ***"The conceptualisation and measurement of adolescent HIV self-management in a South African context,"*** has been checked for inconsistencies in the grammar, punctuation, spelling, syntax and referencing (Harvard).

APPENDIX 13: SAMPLE SIZE CALCULATION

http://www.sample-size.net/correlation-sample-size/



Correlation sample size

Total sample size required to determine whether a correlation coefficient differs from zero.

Instructions: Enter parameters in the red cells. The answer will appear in blue below.

α (two-tailed) =	0.050	*Threshold probability for rejecting the null hypothesis. Type I error rate.*
β =	0.200	*Probability of failing to reject the null hypothesis under the alternative hypothesis. Type II error rate.*
r =	0.180	*The expected correlation coefficient.*

Calculate

The standard normal deviate for $\alpha = Z_\alpha = 1.960$
The standard normal deviate for $\beta = Z_\beta = 0.842$
$C = 0.5 * \ln[(1+r)/(1-r)] = 0.182$

Total sample size = N = $[(Z_\alpha+Z_\beta)/C]^2 + 3 = 240$

Reference: Hulley SB, Cummings SR, Browner WS, Grady D, Newman TB. Designing clinical research : an epidemiologic approach. 4th ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2013. Appendix 6C, page 79.